

# Out of Reach

*Barriers faced by parents/guardians of family based children  
infected/affected by HIV/AIDS to access services for children:  
A situation analysis in four districts of Maharashtra*



आरोग्य, ऊर्जा, शिक्षण आणि पालकत्व  
या विषयांतील विशेष प्रयत्न





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प्रयास

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A situation analysis in four districts of Maharashtra**

By PRAYAS Health group



आरोग्य, ऊर्जा, शिक्षण आणि पालकत्व  
या विषयांतील विशेष प्रयत्न

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We hope that the relentless efforts of everyone involved in this endeavor will bring about a positive change in the lives of children affected and infected by HIV/AIDS.

## Abbreviation

AIDS	: Acquired Immune-deficiency Syndrome
ALHIV	: Adolescents Living with HIV
ART	: Antiretroviral Treatment
CABA	: Children Affected by AIDS
CBO	: Community Based Organization
CI	: Confidence Interval
CLHIV	: Children Living with HIV
CP	: Child Protection
CWC	: Child Welfare Committee
DAC	: Department of AIDS Control
DAPCC	: District AIDS Prevention & Control Committee
DAPCU	: District AIDS Prevention and Control Unit
DHS	: Directorate of Health Services
DPO	: District Program Officer
DWCD	: Department of Women & Child Development
FGD	: Focus Group Discussion
FSW	: Female Sex Worker
GR	: Government Resolution
HIV	: Human Immunodeficiency Virus
ICDS	: Integrated Child Development Services
ICPS	: Integrated Child Protection Scheme
ICTC	: Integrated Counseling and Testing Centre
IDU	: Injecting Drug User
IEC	: Information, Education and Communication
IQR	: Inter-Quartile Range
LAC	: Link ART Centre
LFU	: Lost to Follow-up
MDACS	: Mumbai Districts AIDS Control Society
MSM	: Men who have Sex with Men
MSACS	: Maharashtra State AIDS Control Society
NACO	: National AIDS Control Organization
NGO	: Non-Government Organization
NHM	: National Health Mission
NRHM	: National Rural Health Mission

OI	:	Opportunistic Infections
OPD	:	Out Patient Department
ORW	:	Out Reach Worker
PLHA	:	People Living with HIV/AIDS
PPTCT	:	Prevention of Parent to Child Transmission
RGJBY	:	Rajeev Gandhi Jeevandayee Bima Yojana
SACS	:	State AIDS Control Society
STI	:	Sexually Transmitted Infection
UNDP	:	United Nations Development Programme
UNICEF	:	United Nations Children's Fund
USAID	:	United States Agency for International Development
WHO	:	World Health Organization



## Executive Summary

### Rationale

Children affected by HIV are one of the most marginalized groups among children. Evidence across the globe shows that children affected by HIV/AIDS (CABA) are at increased risk of homelessness, discrimination, exploitation, and loss of life-opportunities. With advent of effective anti-retroviral treatment, children living with HIV are surviving longer, with many now on the verge of transitioning to adulthood. If these children are to contribute as meaningful adults, to themselves as well as to society, health, education, and well-being of these children are of paramount importance. To improve access to these, several schemes have been launched by the government for these children, but there exist barriers that make it difficult for children or their families to reach out to such support systems.

A large proportion of CABA are family-based. The HIV status of the family and the children is unlikely to be disclosed to service providers or in the community for fear of stigma and discrimination. This makes outreach and advocacy for these children even more challenging.

India is home to around 2.09 million PLHA. The state of Maharashtra is one of the high-burden states in India. There are an estimated 315,000 people living with HIV in the state, of which 28,982 are children living with HIV. There would be many more HIV-affected children; these are not infected with HIV, but one or both of their parents are/were infected with HIV.

With the support of UNICEF, Prayas, an NGO based in Pune undertook a situation analysis to understand the current status of health, and education of family-based HIV-infected, and HIV-affected children, and the barriers faced by the parents/guardians of these children to access mainstream services for health, education, nutrition, social and child protection services. The assessment was undertaken with the anticipation that such knowledge would help in strengthening efforts by the government and other stakeholders to protect and promote the rights of these children.

### Methodology

The assessment was undertaken in 4 districts of western Maharashtra viz. Pune, Mumbai, Solapur, and Sangli. It had the following components -

- A. A cross-sectional survey with care givers (parents/guardians) of family-based HIV-infected or HIV-affected children in the 6 – 18 years age group. Survey participants were recruited through community based organizations (CBO)/ positive people's networks / non-government organizations from these districts (NGO). (Number of participants - 510).
- B. Focused group discussions (FGD) with organizations (CBOs/networks of positive people/ NGOs) facilitating linkage of CABA to different services. (Number of participants – 25).
- C. Interviews with managers of government departments providing services for children. (Number of participants -23).
- D. Mapping the availability of existing services for children.

### Important Findings

The majority of care givers that participated in the survey were from low socio-economic strata. There was an equal representation of urban and rural areas. These care givers looked after a total of 883 HIV-infected and HIV-affected children. Data of a single infected/affected child from each household (n=510) were considered for further analysis.

A high proportion of children (8%) were currently out of school; the majority after completing primary education. Several independent risk factors for school drop-out were identified, viz. being

HIV-infected, older age (>13 years), being single/double orphan, lower education of parents, and being looked after by a single parent/grandparent/other relatives. Presence of HIV infection accentuated the risk of dropping out of school, for each of the independent risk factors. HIV-infected children showed greater lag in reaching age-appropriate standard at school. The child's or parent's illness was the most common reason for gap/discontinuation of schooling among HIV-infected children. Other reasons identified were disinterest in education, repeated failures, cost of schooling, need for the child to start earning/to take up household responsibilities/to care for sibling, migration, stigma and discrimination at school, and financial constraints. Subtle levels of stigma and discrimination at schools were reported.

A very high illness burden was seen in these children, especially among HIV-infected ones. A large proportion of cases sought treatment for routine illnesses at private health care facilities. Expenses for hospitalization were often met by borrowing money or selling household assets/gold. All infected children were linked to ART centers; however the existing psycho-social support mechanisms available for these children were deemed inadequate. Most of these children had perinatally acquired HIV. The median age at HIV diagnosis was 6 years. The time lag between diagnosis of index case in the family and testing the child was not more than a year. It probably points towards a lost opportunity of screening mother during pregnancy. This however has to be seen in the light that these were older children and at the time of their birth PPTCT program was in the early phase of roll out.

The majority (60%) of children were orphans. Single mother was the predominant care giver in these households. Maternal family of the child played an important role in taking care of these children. Women and children were denied their rightful share of the family property after the death of child's father. Awareness about social benefit schemes was low. Many caregivers lacked basic documents that were essential to access the benefits. Complexity of the registration procedure was a major barrier to access social welfare benefits. The number and distribution of children's homes in the state that cater to CABA was inadequate and not uniform.

### **Conclusions and the way forward**

This situation analysis showed high levels of educational disadvantages among family-based HIV-affected and HIV-infected children. As compared to HIV-affected children, the educational outcomes (gap in schooling and school drop-out rates) of HIV-infected children are worse. There is a rapid drop-out from schools among CABA, especially after 13 years of age. Ill-health of parents and children is a concern in these households. Illness/death of one or both parents, severe financial constraints, stigma and discrimination by the family and community put these children at a high risk of falling out of the safety net.

Providing more support to HIV-infected children is essential. There is a need to focus on skills development of older CABA and economic support to families for continuation of their education. Children with overlapping risk factors and those lagging behind in school need to be actively reached out through different avenues such as ART centers, community-based organizations, and outreach workers. Sustained efforts to sensitize schools are needed to achieve 'zero discrimination'. The challenge of including the large number of private (unaided) schools in such initiatives needs special attention. Early diagnosis, linkage to HIV care, and retention in HIV care is crucial. Support for travel to ART centers could go a long way in ensuring retention in care. Pediatric counseling services could be strengthened through collaborations with civil society organizations. There is a need to use all available avenues to disseminate information about social benefit schemes to increase awareness. This information needs to be presented in an easy-to-understand format.

An important observation emanating from this situation analysis is that the efforts to improve health, education and well-being of these children cannot be done in isolation of each other. Apart from providing health care, HIV programs in the country need to strengthen their coordination with non-health services such as education, social welfare and child protection services. Pro-active steps by all the concerned departments and combined efforts by government and non-government agencies working for the cause would play a crucial role in reducing the vulnerability and ensuring wellbeing of these children.

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Data collection instruments - [http://www.prayas pune.org/health/images/weblink\\_doc\\_final.pdf](http://www.prayas pune.org/health/images/weblink_doc_final.pdf).

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## Introduction

### Scale of the problem

HIV/AIDS continues to be a major public health issue worldwide. Globally, in 2013, there were 35 million people living with HIV (PLHA). Of these, 3.2 million were children below 15 years (CLHIV)[1]. There were 17.8 million children orphaned by AIDS.

Children affected by HIV/AIDS (CABA) are generally categorized into different groups; viz.

1. Children infected by HIV – These are infected by HIV.
2. Children affected by HIV – These children are not infected with HIV, but at least one of their parents is/was infected with HIV.

*(Some people have used another term ‘children orphaned by AIDS’ for children who have lost one/both the parents due to AIDS. Children orphaned due to AIDS could be either HIV-infected or HIV-affected.)*

3. Vulnerable children – These children are more vulnerable to getting infected with HIV. They include street children, child prisoners, children of sex workers, orphans who have been abandoned by the family etc. HIV status of these children and their parents is generally not known.

In the context of the current situation analysis we have restricted the use of the term CABA to represent only the first two groups as the programmatic emphasis for the third group is completely different. Prevention of new HIV infection is the primary goal of programs for ‘vulnerable children’, whereas mitigation of the impact of HIV/AIDS is the primary goal for the remaining two groups.

India is home to around 2.09 million PLHA which makes it the country with third-highest number of PLHA. Of these, 39% are women and 7 % are children [2]. The proportion of orphans among HIV-infected children is quite high [3]. These children are located mostly in the high HIV-burden states of south and northeast India [4].

There are no clear estimates of CABA in the country.

### HIV-specific vulnerabilities of children

HIV disease has a complex influence on the lives of CABA. HIV-infected households bear heavy financial burdens owing to medical expenses, loss of income due to death or illness of earning member, and unemployment [5]. The extended family is generally not supportive. These children face stigma and discrimination from the community as well as the family members [6, 7]. These challenging circumstances can put the children at increased risk of homelessness, discrimination, exploitation, and loss of life opportunities [8, 9]. A systematic review by Guo et al shows higher educational disadvantage (in terms of school enrollment and attendance, school behavior and performance, school completion, and educational attainment) among CABA compared to other children. Other factors such as resource constraints, being an orphan, relationship with the care giver and external assistance also play an important role. [10]. In general, CABA are burdened with work and family responsibilities at a younger age due to death or illness of parents. These vulnerabilities may get exaggerated for girls, children from poor households, or from marginalized communities such as children of female sex workers (FSWs),

men having sex with men (MSM) and injecting drug users (IDUs) [11]. Like all children, CABA have the right to survival, development, and wellbeing [12], however their exaggerated vulnerability is likely to deprive them of their basic rights.

The protection of children's rights is the responsibility of parents and, in their absence, of the extended family. The state is obliged to help parents/guardians in this role by taking appropriate legislative and administrative measures [7]. In case of orphans the responsibility of caring lies with the community and the state. There has been a paradigm shift in how programs address challenges faced by CABA. The earlier focus of service provision to an individual child has now shifted to a family- and community-centered approach by linking adults and children to antiretroviral therapy (ART), legal support, food and nutrition assistance, and social protection entitlements [11].

### **Child rights and access of CABA to service for children: Indian scenario**

India, as a signatory to the international convention on the rights of children, is committed to protecting vulnerable children from adversities. The Ministry of Women and Child Development, India, and National AIDS Control Organization [12] acknowledge the need to realize the basic rights of CABA in its *Policy Framework for Children and AIDS*. Child protection (CP) strategies for CABA are based on the principles of equity, age-sensitive and participatory interventions, and on prevention of stigma and discrimination [13].

The government commits itself to provide for health, education, nutrition, and protection to children. The Indian national program for HIV/AIDS provides free HIV testing and care and support (including ART) services [14]. Apart from the HIV-specific services, general health care is offered free of cost at all government health care facilities. Like all children in the country, CABA are entitled to free and compulsory primary education. Various social benefit schemes are provided to poor households to assist them in their financial needs. Similarly, various non-institutional and institutional services are provided for child protection.

In spite of these commitments, HIV-related activities for children have largely remained focused on prevention of the infection and provision of health care. The independent Commission on AIDS in Asia [15] points out that, attempts to involve non-health sectors – especially education and social welfare – have generally been unsuccessful in this region. Limited information is available about the extent of barriers faced by family-based CABA in accessing mainstream services from non-health sectors.

There have been only a few studies from India which have documented the disadvantages faced by CABA in accessing mainstream services such as health, education, social benefit schemes, etc. The majority of these were done at a time when ART was not widely available in the country. A qualitative study [6] from 5 high-prevalence states reported that stigma and discrimination at schools was a major barrier in continuation of education of these children. Children and their parents were excluded from services such as health care, and food-aid programs. The study also pointed out that service providers were largely unaware of these barriers. In 2006, National AIDS Control Organization (NACO) commissioned a study to assess socio-economic impact of HIV and AIDS. The study was conducted in the six high HIV-prevalence states of India [5]. This assessment found that a higher proportion of 6-14 years old children from HIV-affected households had dropped out of schools compared to other children (3.49% vs. 1.76%). The proportion of school drop-outs was much higher (27%) in older children from HIV-affected households. Inability to afford was the major reason for school drop-out. Only 15% of the participants (parents of these children) were taking ART. The study did not differentiate the educational outcomes by HIV status of the children.



HIV-infected children have been reported to be prone to recurrent illnesses, malnutrition [16] and HIV associated neuro-cognitive impairment [17]. This may adversely affect their educational status. However, limited information is available on the educational needs of this group.

A large proportion of CABA are family-based. The HIV status of the family and the children is unlikely to be disclosed to service providers or in the community for fear of stigma and discrimination. So, as a group this remains largely an invisible one. This makes understanding and quantifying the needs of this group as well as outreach and advocacy difficult.

With this background Prayas, an NGO based in Pune, undertook a situation analysis to get an in-depth understanding of the barriers faced by parents/guardians of family-based HIV-infected and affected children to access services. The situation analysis was undertaken in the state of Maharashtra and was supported by UNICEF.

## Objectives

### Primary objectives -

- To estimate the magnitude of school non-enrollment, school drop-out, and highest educational attainment (years of formal schooling) among family-based HIV-affected/infected children.
- To understand the barriers faced by care givers of family-based children affected/infected with HIV to access services for children.
- To understand the barriers faced by other stakeholders (such as organizations working for CABA, managers of government departments) involved in provision of services to these children.

Children staying on their own or in institutions or street children were not considered for this assessment.

### Secondary objectives –

- To understand the socio-demographic determinants of school non-enrollment and school drop-outs among these children.
- To document information on the best practices to overcome the barriers faced by CABA while accessing services for children, and social welfare schemes.
- To understand the current availability of services of health, education, HIV care and support and other child protection services in the state

## Approach

### Definitions of terms used for the analysis

HIV-infected children– Children infected and living with HIV

HIV-affected children– Living children, not-infected or not tested for HIV and having one or both parents infected with HIV (living or dead)

Care giver – Parent or guardian of the child who currently plays a major role in looking after the child

Enrolled in school – A child enrolled in a government or private pre-school or school

Out of school – A child that was never enrolled in school or a child that was enrolled, but dropped out from school

Social protection entitlements – Services that strengthen families so that the child's vulnerability is reduced

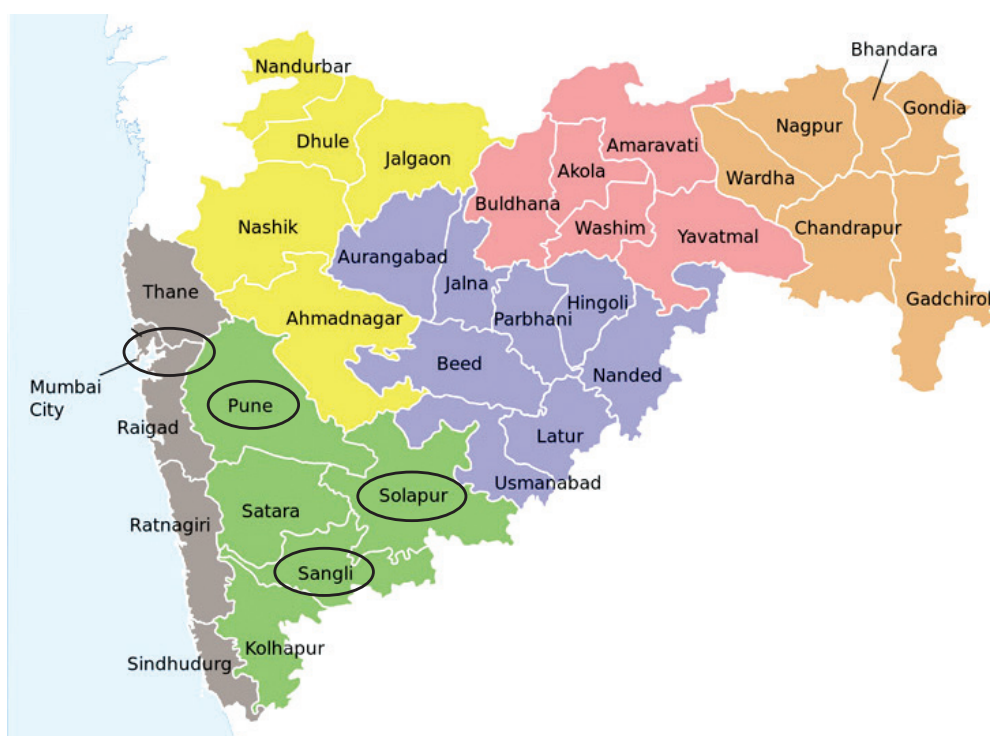
Child protection services – Services that reduce vulnerabilities of children to any kind of harm and ensure that the child does not fall out of safety net and those who do, receive necessary care protection and support services so as to bring them back into safety net (as explained in Integrated Child Protection Scheme)

### Assessment area

The assessment was undertaken in 4 districts of western Maharashtra viz. Pune, Mumbai, Solapur, and Sangli.

The state of Maharashtra is one of the high-burden states in India, contributing to 15% of the estimated total of HIV cases in the country [2]. There are an estimated 3,15,000 PLHIV in the state; of which 28,982 are CLHIV [18].

**Figure 1 : Assessment area**



**Table 1 : Profile of the districts where the assessment was undertaken**

	Mumbai*	Pune	Sangli	Solapur
Total population [19]	12,478,447	9,429,408	2,822,143	4,317,756
Urban	-	5,751,182	719,357	1,399,091
Rural	-	3,678,226	2,102,786	2,918,665
HIV-prevalence [18]	0.75	0.67	0.38	0.63

\*Greater Mumbai

### Rationale behind choosing the assessment area -

All the four districts are classified by NACO as category ‘A’ districts; with HIV-prevalence of more than 1% among pregnant women. The infrastructural development in all these districts is relatively better-off compared to other less developed areas in the state. It is presumed that the vulnerabilities of children from underdeveloped regions would be at least the same, if not worse than in the ‘developed’ districts. The budget- and time- constraints also guided the decision about the study area.

Each of these districts has some unique features worth a mention. Districts such as Pune and Mumbai have a large urban population. A significant proportion of people live in slums, many are migrants coming from various states of India. These districts also have a number of health care facilities that provide specialized HIV care. Solapur district is situated on the border of Maharashtra and Andhra Pradesh. A lot of cross-border migration is seen in this district, and it is one of the highest HIV-prevalence areas in the state. Sangli district has its unique *devdasi*-based sex work industry and was one of the worst-hit districts in the initial phase of the epidemic.

### Methods

A mixed-methods approach was used.

- A. A cross-sectional survey with care givers of family-based, 6-18 years old HIV-infected or HIV-affected children was undertaken to understand the educational outcomes of children, their health status, treatment-seeking behaviors, uptake of other services, and barriers faced by the care givers to access services for children.

The barriers of other stakeholders involved in provision of services to children were assessed by-

- B. Conducting Focused Group Discussions (FGD) with organizations (CBOs/networks of positive people/NGOs) facilitating linkage of CABA to different services
- C. Undertaking interviews with managers of government departments providing services for children
- D. Mapping availability of existing services for children

## A. Cross sectional survey -

### *Eligibility criteria*

An adult care giver who is currently looking after family-based 6-18 year old HIV-infected or affected child/ren was eligible to participate. Households that had no adult member and were headed by the child/ren were excluded from the survey.

### *Sample size calculation*

The sample size calculations for the survey were based on the pilot data on educational status among CLHIV seeking care at HIV care clinic at Prayas. The sample size of 250 HIV-infected and 250 HIV-affected children was arrived at by assuming a school drop-out rate of 20%, at 95% confidence level and 10% width of confidence interval.

### *Recruitment procedure*

The participants were approached through non-governmental and community-based organizations working for PLHA, or through positive people's networks from these districts. We enrolled participants who were linked, as well as those unlinked to these organizations. Unlinked participant was defined as a care giver not registered with the organization and visiting for the first time. It was anticipated that children of care givers not registered with any organization may have different outcomes compared to care givers registered with organizations, as the latter had an additional support system.

A comprehensive list of CBOs/networks working for PLHA/NGOs in the district was prepared for all four districts and they were approached. Willing organizations were identified. To have uniform representation, it was decided to recruit equal number of participants from each district. So as to recruit a representative sample from all organizations, the number of participants to be recruited from each, was determined *a priori*. A total of 16 organizations were willing to refer participants for the assessment. Of these, 5 were networks of positive people and 11 were CBO/NGOs. Each organization was requested to prepare a list of eligible care givers. Nine organizations had such lists. Systematic random sampling was attempted in these cases. These lists had 3 types of care givers – care givers looking after

- a) Only HIV-infected children,
- b) Only affected children
- c) Both infected and affected children

The staff of the organizations was trained to select the required number of sample from each of this group. Unwilling participants were replaced by the next candidate in the list. As the participants were approached mainly through CBOs and NGOs, there are no data regarding the refusals. However these organizations reported that the refusal rate was approximately 10%. The main reason for refusal was inconvenience to attend the interview. Five organizations could not provide a comprehensive list of eligible care givers. In case of these, eligible candidates were identified from clients attending support-group meetings. In case of one organization, selection by recall method was used. Some participants were enrolled from private-sector HIV clinic by recruiting consecutive cases attending the clinic. For recruiting unlinked care givers, consecutive new cases were approached prior to registration with the organization.

Confidentiality was strictly maintained. The organizations made first contact with the eligible candidates. The willing candidate was then referred to the study team. Written informed consent was sought. Eligibility of the candidate was confirmed before proceeding with the interview.

A one-time interview using a structured questionnaire was undertaken. Information was collected on socio-demographic profile of care giver and children, educational outcomes of children, health status of children, and health seeking practices, property rights violation, safety, wellbeing of children and awareness/linkage to social benefit schemes. Information on barriers to access services in each of this domain was sought. Any spontaneous information provided by the participants during the interview was captured. This qualitative data was used to supplement the quantitative findings.

*Number of recruited participants –*

We recruited 510 eligible participants for the assessment. Of these, 98 care givers were unlinked to any organization. Following is the district-wise distribution:

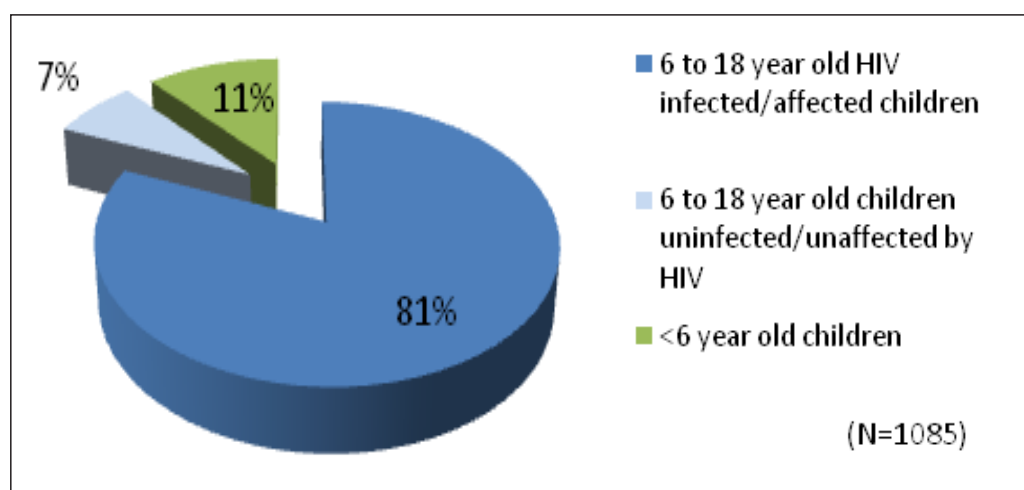
**Table 2 : Number of recruited participants**

	Mumbai	Pune	Sangli	Solapur	Total
Linked	106	99	109	98	412
Unlinked	29	29	23	17	98
Total	135	128	132	115	510

*Total number of children in the households –*

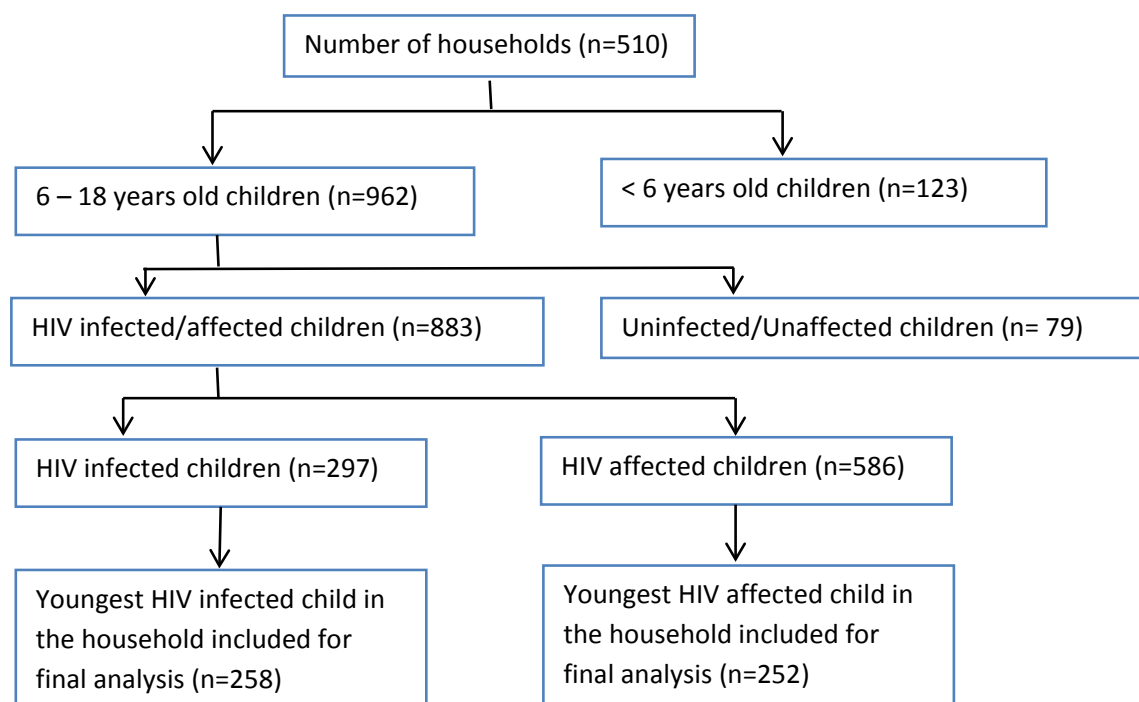
There were a total of 1085 children (< 18 years of age) living in these 510 households. Of these, 883 were within 6-18 years of age and were either HIV-infected or affected. There were 123 children less than 6 years old. There were 79 children in the age group of 6-18 years and were neither HIV-infected nor HIV-affected. These were cousins (brother/sister) of HIV-affected/infected child living in the same household. Information of these 79 children was not collected.

**Figure 2 : Total number of children in the households**



In case of 258 care givers, at least one of the 6-18 year old children they looked after was HIV-infected (group A). In 252 care givers none of 6-18 year old children was HIV-infected (group B). The youngest HIV-infected child from group A and the youngest affected child from group B was considered for further analysis. Two participants from group B had twins. For each case, one of the twins was selected by lottery method.

**Figure 3 : Cases included in the analysis**



- B. Focus Group discussions (FGDs) were conducted to seek information regarding barriers faced by organizations in linking the children to services. FGDs were conducted with representatives of CBOs/network of positive people/NGOs from the study districts. One FGD per district was conducted in the local language. A total of 25 participants from 10 organizations participated in FGDs.
- C. After obtaining prior permission from respective departments, district-level officials from Department of Health, Department of Education, District AIDS Prevention and Control Unit (DAPCU), Mumbai Districts AIDS Control Society(MDACS) and Department of Women and Child Development (DWCD), and state-level officials from Maharashtra State AIDS Control Society (MSACS) were interviewed (Table 3). These interviews aimed at getting a broad understanding of the perceptions of service managers regarding difficulties faced by the CABA while accessing services for children, current strategies/practices to improve outreach of services and the barriers faced.

**Table 3 : Number of interviews with service managers**

	Department	Designation (N)
<b>State level</b>	MSACS	Joint Director, Care Support Treatment (1)
		Regional Coordinator, Care Support Treatment (1)
<b>District level</b>	DWCD	District Women and Child Welfare Officer (3)
		Child Welfare committee, chairperson (1)
	DHS	District Health Officer (1)
		Civil Surgeon (2)
	MDACS	ART officer (4)
		Deputy Director-STI/Deputy Director-Care Support Treatment (2)
	Department of Education	District Primary Education Officer (3) and District Secondary Education Officer (2)
	DAPCU	District Program Officer (3)

- D. Mapping of services – Mapping of currently available services/schemes for children in the state was done by obtaining data from the concerned state departments.

## **Data Analysis**

The quantitative data was analyzed using SAS (version 9.4), SAS Institute Inc., Cary, NC, USA. Only one child per household was selected for data analysis to avoid correlated data of children from one household. Economic status of the household was calculated using Prasad's socio-economic status classification (2014) [20]. Descriptive statistics were used to understand the profile of participants, uptake of services, and barriers faced. Chi square/Fisher exact test was used to understand differences in educational outcomes across different subgroups. For analysis of qualitative data verbatim text collected during the interviews was transcribed, coded and analyzed using MAXQDA (version 11). The relevant quotes were then translated for inclusion in the report.

## **Ethical issues**

The situation analysis was approved by Prayas Institutional Ethics Committee. Participation in the assessment was voluntary and written informed consent of each participant was obtained. All efforts and precautions were taken to maintain confidentiality of the participants. Wherever needed, participants were linked to appropriate psychosocial services.



## Results

This section provides the socio-demographic profile of eligible care givers and children, domain specific (health, education, child protection) information of children and barriers faced by the care givers and organizations in linking these children to services. Lastly it provides innovative practices adopted by the organizations, services available and specific strategies adopted by service managers, if any.

### Profile of care givers

Socio-demographic information of care givers who were interviewed during this assessment is given in table 4. Majority of these care givers were parents (88%) or grandparents (7%). Ninety seven percent of mothers and 94% of fathers were HIV-infected. None of the grandparents/other relatives interviewed during assessment was HIV-infected.

**Table 4 : Socio-demographic profile of care givers**

	<b>Mumbai</b> N (%)	<b>Pune</b> N (%)	<b>Sangli</b> N (%)	<b>Solapur</b> N (%)	<b>Total</b> N (%)
<b>Total</b>	<b>135 (26)</b>	<b>128 (25)</b>	<b>132 (26)</b>	<b>115 (23)</b>	<b>510 (100)</b>
<b>Gender (n=510)</b>					
Male	40 (30)	21 (16)	27 (20)	29 (25)	117 (23)
Female	95 (70)	107 (84)	105 (80)	86 (75)	393 (77)
<b>Area of residence (n=510)</b>					
Rural	2 (1)	84 (66)	104 (79)	73 (63)	263 (51.5)
Urban	21 (16)	26 (20)	24 (18)	20 (17)	91 (18)
Urban slum	112 (83)	18 (14)	4 (3)	22 (19)	156 (30.5)
<b>Educational Status (completed standard) (n=510)</b>					
Nil	28 (21)	24 (19)	29 (22)	31 (27)	112 (22)
1 to 7	45 (33)	41 (32)	42 (32)	34 (30)	162 (32)
8 and above	62 (46)	63 (49)	61 (46)	50 (43)	236 (46)
<b>Marital Status (n=510)</b>					
Married	72 (53)	50 (39)	50 (38)	51 (44)	223 (44)
Widowed	59 (44)	71 (55)	75 (57)	57 (50)	262 (51)
Divorced/separated	4 (3)	6 (5)	7 (5)	6 (5)	23 (4.7)
Unmarried	0 (0)	1 (1)	0 (0)	1 (1)	2 (0.3)

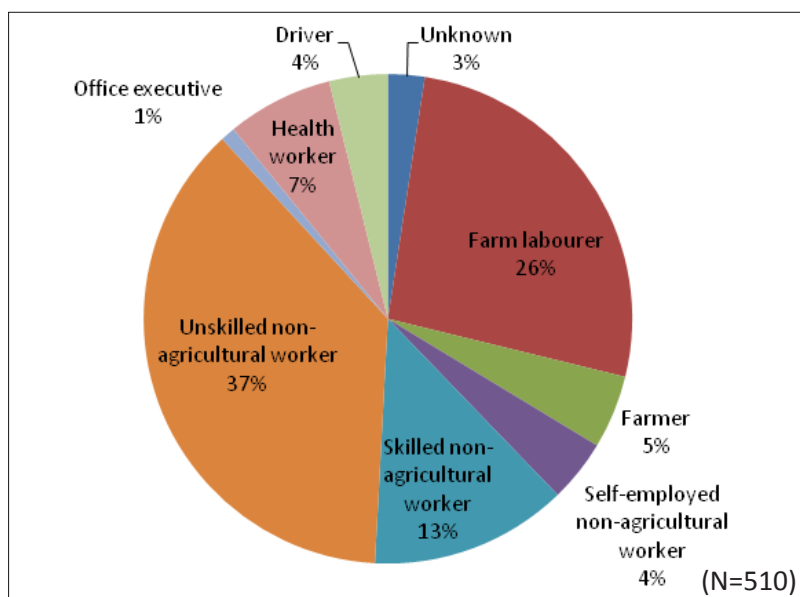
<b>Occupation (n=510)</b>					
Unemployed	17 (13)	11 (9)	17 (13)	10 (9)	55 (11)
Employed	102 (76)	101 (79)	111 (84)	99 (86)	413 (81)
Housewife	16 (12)	16 (13)	4 (3)	6 (5)	42 (8)
<b>Economic category (n=510)</b>					
Lower	98 (73)	96 (75)	118 (89)	109 (95)	421 (83)
Middle	26 (19)	16 (13)	10 (8)	4 (3)	56 (11)
Upper	11 (8)	16 (13)	4 (3)	2 (2)	33 (6)
<b>Religion (n=510)</b>					
Hindu	112 (83)	119 (93)	129 (97.6)	108 (94)	468 (91)
Muslim	19 (14)	4 (3)	1 (0.8)	5 (4)	29 (6)
Other	4 (3)	5 (4)	2 (1.6)	2 (2)	13 (3)
<b>Type of house (n=507)</b>					
Kutchha	10 (7)	34 (27)	43 (33)	64 (56)	151 (30)
Pucca	124 (93)	93 (73)	88 (67)	51 (44)	356 (70)
<b>Presence of at least one household asset (n=510)*</b>					
No	23 (17)	36 (28)	62 (47)	55 (48)	176 (35)
Yes	112 (83)	92 (72)	70 (53)	60 (52)	334 (65)
<b>Color of ration card (n=508)</b>					
White	3 (2)	9 (7)	1 (1)	2 (2)	15 (3)
Orange	96 (71)	77 (60)	80 (61)	58 (50)	311 (61)
Yellow	28 (21)	35 (27)	42 (32)	36 (31)	141 (28)
Don't have ration card	8 (6)	7 (5)	7 (5)	19 (17)	41 (8)

\*TV, two-wheeler, four-wheeler

The median age of the care giver was 36 years (IQR - 32 to 40 years), and 77% were women. There was an equal representation of urban and rural areas. A large proportion of urban care givers resided in slums. Most of the slum dwellers were from Mumbai. Participants in rural area were more or less uniformly distributed across Pune, Solapur and Sangli districts.

Twenty-two percent of care givers were illiterate and 32% had completed schooling up to the 7<sup>th</sup> Standard. Almost half of the participants were working as farm laborers or unskilled non-agricultural workers (Figure 4).

**Figure 4 : Occupation of caregivers**



A large number of care givers were widowed (51%). The proportion of widowhood was much higher (64%) compared to widowers (9.7%). Almost 84% of widowed women were working to earn a livelihood, mostly as unskilled agricultural workers (28%) or unskilled non-agricultural workers (35%).

Majority of the participants were from low socio-economic strata as the sample was recruited through CBO/networks/NGOs working for PLHA in the district whose clientele mainly belongs to this group. Almost one-third of the participants were staying in *Kutchha* houses. One-third did not have any asset in the household such as TV, two-wheeler, or four-wheeler and almost 95% of them belonged to lower/middle economic strata. Twenty-eight percent of the participants possessed a yellow ration card indicating 'below poverty line' status.

Nineteen percent of the care givers were not linked to any of the organizations. There was no difference in socio-demographic profile of those linked or not linked except,

- Linked participants had higher proportion of people from low economic category compared to unlinked participants (85% vs. 70%).
- Proportion of double orphans was higher in the linked group compared to the unlinked ones (11%vs.7%)
- Proportion of grandparents as the only care giver was higher in the linked group compared to the unlinked one (5%vs.2%)

### **Profile of 6-18 years old HIV-affected and infected children –**

Of the total 883 children living in these households, 297 (33.6%) were infected with HIV. The remaining 586 were HIV-affected (60% not infected with HIV and 6.3% not tested for HIV). Almost half (47%) were girls, 55% were 6-13 years of age, and 58% were single/double orphans. (Table 5)

**Table 5 : Socio-demographic profile of all HIV-infected and affected children in the household**

	<b>Affected N (%)</b>	<b>Infected N (%)</b>	<b>Total N (%)</b>
<b>Total</b>	<b>586 (66)</b>	<b>297 (34)</b>	<b>883 (100)</b>
<b>Gender of children (n=883)</b>			
Boy	304 (52)	167 (56)	471 (53)
Girl	282 (48)	130 (44)	412 (47)
<b>Age category of children (n=883)</b>			
6 to 13 years	317 (54)	171 (58)	488 (55)
14 to 16 years	197 (34)	97 (33)	294 (33)
17 to 18 years	72 (12)	29 (9)	101 (12)
<b>Vital status of the parents (n=883)</b>			
Both parents alive	279 (48)	89 (30)	368 (42)
Single parent alive	277 (47)	156 (51)	433 (49)
Both parents expired	30 (5)	52 (19)	82 (9)

As discussed in the Methods section, only one child per household was selected for further analysis.

The following sections provides detailed information of these children (n=510).

The demographic profile of these 510 children is provided in Table 6. There were 258 children infected with HIV. The remaining 252 were HIV-affected. Of these, 227 were un-infected and only 25 were not tested for HIV.

Proportion of girls was a little lower (44%) than boys and 61% of children were orphans (51% were single orphan and 10% were double orphans). Majority of single orphans (92%) had lost their father, 5% had lost the mother. The median age of the child at the time of death of father and mother was 4 years (IQR- 2 to 7 years) and 5 years (IQR-3 to 8 years), respectively. In case of 9 children, the child was looked after by one parent and the vital status of the other parent was unknown as the other parent had left the household. We have included these children as single orphans.

There were a few salient differences in the characteristics of HIV-infected and affected children. HIV-infected children were likely to be older and to have lost both parents. This could be due to survival bias among long-term non-progressors, and a decline in new pediatric infections in recent years.

**Table 6 : Socio demographic profile of HIV-infected/affected children (single child per household)**

	<b>Affected N (%)</b>	<b>Infected N (%)</b>	<b>Total N (%)</b>
<b>Total</b>	<b>252 (49)</b>	<b>258 (51)</b>	<b>510 (100)</b>
<b>Gender of children (n=510)</b>			
Boy	142 (56)	145 (56)	287 (56)
Girl	110 (44)	113 (44)	223 (44)
<b>Age category of children (n=510)</b>			
6 to 13 years	172 (68)	159 (62)	331 (65)
14 to 16 years	63 (25)	78 (30)	141 (28)
17 to 18 years	17 (7)	21 (8)	38 (7)

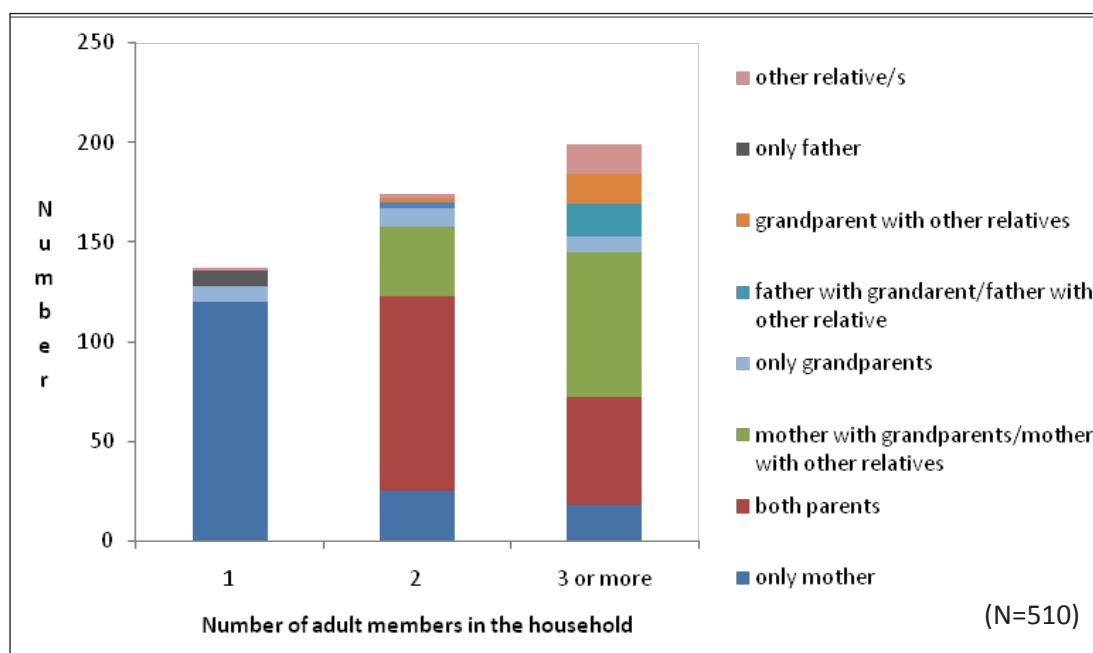
<b>Vital status of the parents (n=510)</b>			
Both parents alive	122 (48)	74 (29)	196 (39)
Single parent alive*	123 (49)	138 (53)	261 (51)
Both parents expired	7 (3)	46 (18)	53 (10)
<b>Total number of siblings (n=510)</b>			
0	81 (32)	91 (35)	172 (34)
1	99 (39)	96 (37)	195 (38)
2	45 (18)	40 (16)	85 (17)
3 or more	27 (11)	31 (12)	58 (11)
<b>Number of HIV-infected siblings (n=510)</b>			
0	248 (98)	218 (84.7)	466 (91)
1	4 (2)	39 (15)	43 (8.8)
2	0 (0)	1 (0.3)	1 (0.2)
<b>Marital status of care giver (n=510)</b>			
Married	117 (46)	106 (41)	223 (43.7)
Widowed	120 (48)	142 (55)	262 (51)
Divorced/separated	15 (6)	8 (3)	23 (5)
Unmarried	0 (0)	2 (1)	2 (0.3)
<b>Area of residence (n=510)</b>			
Rural	142 (56)	121 (47)	263 (52)
Urban	49 (20)	42 (16)	91 (18)
Urban-slum	61 (24)	95 (37)	156 (30)
<b>Education of caregiver (n=510) (completed standard )</b>			
Nil	45 (18)	67 (26)	112 (22)
1 to 7	71 (28)	91 (35)	162 (32)
8 and above	136 (54)	100 (39)	236 (46)
<b>Economic status (n=883)</b>			
Lower	213 (84)	208 (81)	421 (82)
Middle	22 (9)	34 (13)	56 (11)
Upper	17 (7)	16 (6)	33 (7)

*\*In 9 children, child was looked after by one parent and the vital status of the other parent was unknown as the other parent had left the household.*

## **Who is the care giver in the family?**

One or more members of the family were taking care of the child in these households. Around one third of households had only one adult member. Single mother (88%) was the predominant care giver in these households. Both parents were the primary care givers in 40% households with 2 or more adult members. Overall, maternal family of the child played an important role in taking on the responsibility of orphaned children (Figure 5).

**Figure 5 : Who is the care giver/s in the family?**



**Access to services for children and barriers faced**

**Education of children**

*School enrollment -*

Almost all children (99.41%) were enrolled in school (Table 7). Of the 3 ‘not enrolled’ children, one was 6 years old and was not enrolled as the family got migrated. The remaining two were older (10 and 16 years of age), and HIV infected. One of the boys was mentally challenged and so was not enrolled in school. The other boy had lost his mother when he was 7 years old and was not enrolled as there was no one at home to look after him.

*Out of the school children –*

Among 507 children who were ever enrolled in school, 29 (5.7%) dropped out. Thus there were a total of 6.2% (95% CI = 4.4%-8.7%) children currently ‘out of school’ (Table 7). The proportion of out-of-school children was much lower among HIV-affected children (1.5%, 95% CI = 0.6-4) compared to HIV-infected ones (10.8%, 95% CI = 7.6-15.2).

**Table 7 : Schooling status of children**

	HIV-affected N (%)	HIV Infected N (%)	Total N (%)
Not enrolled	1 (0.4)	2 (0.7)	3 (0.6)
Enrolled but currently not going to school	3 (1.2)	26 (10.1)	29 (5.7)
Out of school *	4 (1.5)	28 (10.8)	32 (6.2)

\*Out of school (Not enrolled + Enrolled but currently not going to school)

Proportion of children currently out of school, across different subgroups is provided in Table 8. Higher proportion of HIV-infected children (10.8%) were out of school compared to HIV-affected children (1.5%) ( $p < .0001$ ). Among 6-13 years old children, 1.2% were out of school. This proportion acutely increased to 13.4% and 23.6% among older children aged 14-16 and 17-18 years respectively ( $p < .0001$ ). Single orphans (6.5%) or double orphans (15%) were more likely to be out of school compared to children living with both parents (3.5%) ( $p = 0.008$ ). A higher school drop-out rate was seen among children looked after by 'only father' (25%), 'only grandparents' (12%), and 'grandparents with or without other relatives' (17%). The drop-out rate was relatively lower among children cared for by 'both parents' (2.6%), 'only mother' (5.5%), and single parent with other family members (6.3%) ( $p = 0.0005$ ). Educational status of parents influenced schooling status of the child. Children of care givers who were illiterate (12.5%) were more likely to be out of school compared to children of care givers who had completed 7<sup>th</sup> standard or more (6.7%, 2.9% respectively) ( $p = 0.002$ ). A marginally higher proportion of children from rural areas (7.9%) and urban slums (5.1%) were out of school compared to urban areas (3.3%) ( $p = 0.2$ ). Similarly, higher proportions of out-of-school children were seen in Muslims (13.7%) compared to Hindus (5.7%) ( $p = 0.15$ ). There were no differences across various categories of gender, economic categories, type of school, and linkage to organization.

**Table 8 : Determinants of being 'out of school'**

Variables	N	Currently going to school N(%)	Currently not going to school N(%)	P-value
<b>HIV Status of the children</b>				<.0001
Affected	252	248 (98.4)	4 (1.5)	
Infected	258	230 (89.1)	28 (10.8)	
<b>Gender of children</b>				0.99
Boy	287	269 (93.7)	18 (6.2)	
Girl	223	209 (93.7)	14 (6.2)	
<b>Age of children</b>				<.0001
6 to 13 years	331	327 (98.7)	4 (1.2)	
14 to 16 years	141	122 (86.5)	19 (13.4)	
17 to 18 years	38	29 (76.3)	9 (23.6)	
<b>Vital status of parents</b>				0.008
Both parents alive	196	189 (96.4)	7 (3.5)	
Single parent alive	261	244 (93.4)	17 (6.5)	
Both parents expired	53	45 (84.9)	8 (15.0)	
<b>Type of school</b>				0.44
Government	275	265 (96.3)	10 (3.6)	
Private	217	212 (97.7)	5 (2)	
<b>Who is the care giver in the family?</b>				
Both parents	152	148 (97.3)	4 (2.6)	0.0054
Only mother	163	154 (94.4)	9 (5.5)	
Only father	8	6 (75)	2 (25)	
Single parent with grandparents/single parent with other relatives	127	119 (93.7)	8 (6.3)	

Only grandparent	25	22 (88)	3 (12)	
Grandparent with other relatives/ other relatives	35	29 (82.8)	6 (17.1)	
<b>Education of care giver (completed standard)</b>				0.002
Nil	112	98 (87.5)	14 (12.5)	
1 to 7	162	151 (93.2)	11 (6.7)	
8 and above	236	229 (97)	7 (2.9)	
<b>Area of residence</b>				0.25
Rural	263	242 (92)	21 (7.9)	
Urban	91	88 (96.7)	3 (3.3)	
Urban slum	156	148 (94.8)	8 (5.1)	
<b>Religion</b>				0.15
Hindu	468	441 (94.2)	27 (5.7)	
Muslim	29	25 (86.2)	4 (13.7)	
Other	13	12 (92.3)	1 (7.6)	
<b>Economic status</b>				0.61
Lower	421	396 (94)	25 (5.9)	
Middle	56	51 (91)	5 (8.9)	
Higher	33	31 (93.9)	2 (6)	
<b>Linked to organization</b>				
No	98	92 (93.8)	6 (6.1)	0.94
Yes	412	386 (93.6)	26 (6.3)	

(Note - Out of school = children not enrolled in school + children enrolled but currently not going to school).

HIV-infected children appeared to have an accentuated risk of being out of school for each of the independent risk factors (Table 9).

**Table 9 : Proportion of ‘out of school’ children by HIV status of the child**

Variable		HIV-affected N(%)	HIV-infected N(%)
<b>Total</b>		<b>4 (1.5)</b>	<b>28 (10.8)</b>
<b>Gender of child</b>	Boy	4 (2.8)	14 (9.6)
	Girl	0 (0)	14 (12.3)
<b>Age of the child</b>	6 to 13 years	1 (0.5)	3 (1.8)
	14 to 16 years	2 (3.1)	17 (21.7)
	17 to 18 years	1 (5.8)	8 (38.1)
<b>Vital status of the parents</b>	Both parents alive	2 (1.6)	5 (6.7)
	Single parent alive	1 (0.8)	16 (11.5)
	Both parents expired	1 (14.2)	7 (15.2)
<b>Type of school</b>	Government	1 (0.81)	9 (5.9)
	Private	1 (0.7)	4 (4.4)



<b>Caregiver in the family</b>	Both parents	2 (2)	2 (3.7)
	Only mother	1 (1.3)	8 (9.3)
	Only grandparent	0 (0)	3 (13.6)
	Only father	0 (0)	2 (40)
	Single parent with grandparents/single parent with other relatives	0 (0)	8 (13.7)
	Grandparent with other relatives/other relatives	1 (25)	5 (16.1)
<b>Education of care giver (completed standard)</b>	No schooling	2 (4.4)	12 (17.9)
	1 – 7	1 (1.4)	10 (10.9)
	Above 7	1 (0.7)	6 (6)
<b>Area of residence</b>	Urban	1 (2)	2 (4.7)
	Rural	2 (1.4)	19 (15.7)
	Urban Slum	1 (1.6)	7 (7.3)
<b>Religion</b>	Hindu	4 (1.7)	23 (9.7)
	Muslim	0 (0)	4 (26)
	Other	0 (0)	1 (14.2)
<b>Economic status</b>	Lower	3 (1.4)	22 (10.5)
	Middle	1 (4.5)	4 (11.7)
	Upper	0 (0)	2 (12.5)
<b>Linked to organization</b>	No	1 (2.7)	5 (8)
	Yes	3 (1.3)	23 (11.7)

*Out of school = not enrolled in school + enrolled but currently not going to school.*

Any household characteristic that adversely impacts the education of a child would affect all children in the household. In the study cohort, the proportion of HIV-affected children in a household was almost twice that of HIV-infected children. To get an overall understanding of the magnitude of the problem, data of all 883 children (586 affected and 297 infected) living in these households was analyzed. It showed that the proportionate increase in school drop-outs among affected children was higher compared to infected children, there by narrowing the gap between the two subgroups. The overall proportion of out-of-school children in the entire cohort of 883 children was 8.4% (95% CI=6.8-10.5). It was 7.0% (95% CI= 5.1-9.3) among affected children and 11.4% (95% CI= 8.3-15.5) among infected ones.

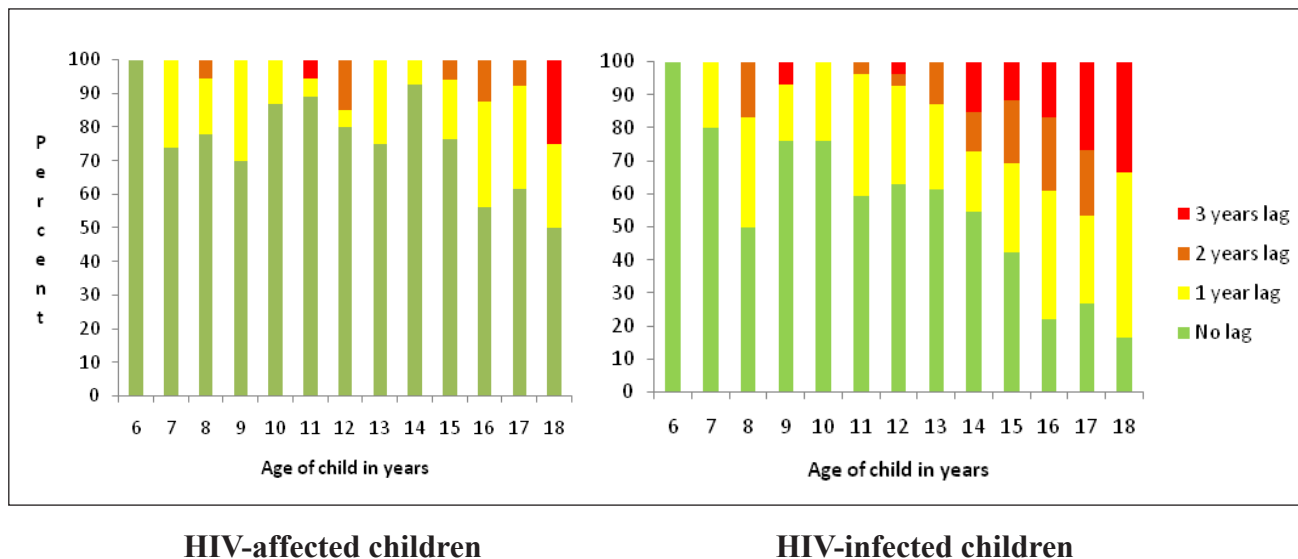
#### *Age-appropriate standard of schooling*

The highest standard completed among school drop-outs was 7<sup>th</sup> (IQR – 6<sup>th</sup> to 9<sup>th</sup>)

To determine eligibility for admission to school, different schools employ different cut-off dates to decide completed years of age. There is no uniform age-eligibility criterion for school admission. Thus some children became eligible after completing 5 years, some after 6 years. A child who has completed 7 years of age can thus be expected to be in the 1<sup>st</sup> or 2<sup>nd</sup> standard. We have applied this logic to interpret the highest education attained, and the lag behind the age appropriate standard. Figure 6 shows the proportion of children lagging behind the expected standard against age of the child. Higher number of HIV-infected children (44%) has lagged behind the age appropriate standard compared to affected

children (21%). A lag of more than one year was seen in 17% of HIV-infected children. Compared to this, only 4% affected children showed such a lag.

**Figure 6 : Proportion of children lagging behind the age appropriate standard by HIV status of the child**

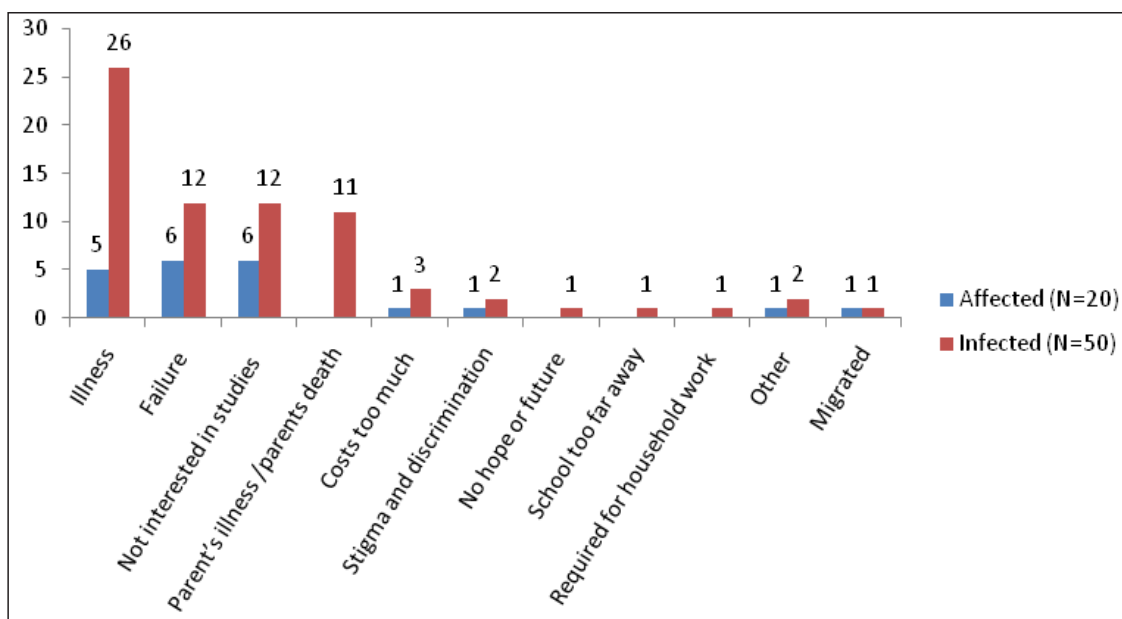


*Reason for gap in schooling, or discontinuation of education*

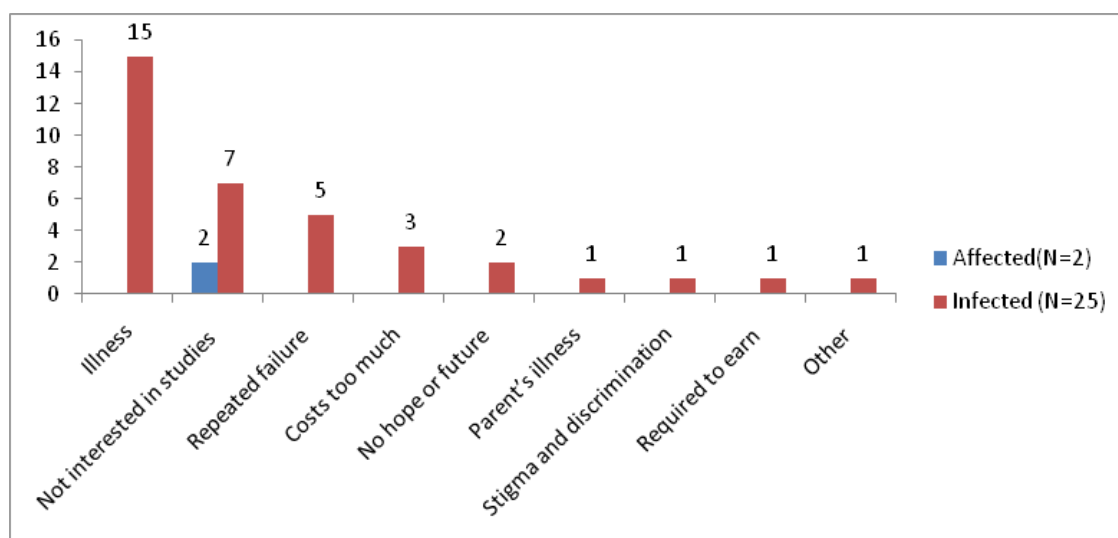
We had asked care givers if the child had taken a gap of more than a year when in school. This question was asked for currently-in-school children, as well as drop-outs who ever attended school.

Among HIV-infected children, child’s or parent’s illness were common reasons for taking a gap during schooling, or not continuing education. Apart from this, disinterest in school and repeated failure, were also reported. In affected children, failure or disinterest in studies were common reasons for taking a gap/discontinuation (Figure7 and 8).

**Figure 7 : Reasons for gap in schooling**



**Figure 8 : Reasons for discontinuation of education**



*“He (my child) gets fever occasionally. So misses his school often. He then cannot concentrate in school. So (we) stopped his school.”*

(35 year old woman, widow, mother of 15 year old HIV-infected boy)

We also looked at data of siblings of these children who had taken a gap/discontinued the school. A few other reasons such as cost of schooling, need for the child to start earning/to take up household responsibilities/to care for sibling, migration, and stigma and discrimination at school were also identified.

Financial constraints also played an important role. Many parents were unable to afford fees for continuing education after secondary school. This was especially troublesome for orphans staying with grandparents or other relatives.

*“The atmosphere in these households is saddening.....because of so many things ..... parent’s illness, child’s illness, financial problems. (Parents) need to take leave from their work to go to ART center, or because of illness. Hence work gets affected. They can’t provide for expenses for schooling .....or for household necessities. They can’t even give sufficient nutrition to children. This all makes a lot of impact.”*

(FGD participant from Pune, female)

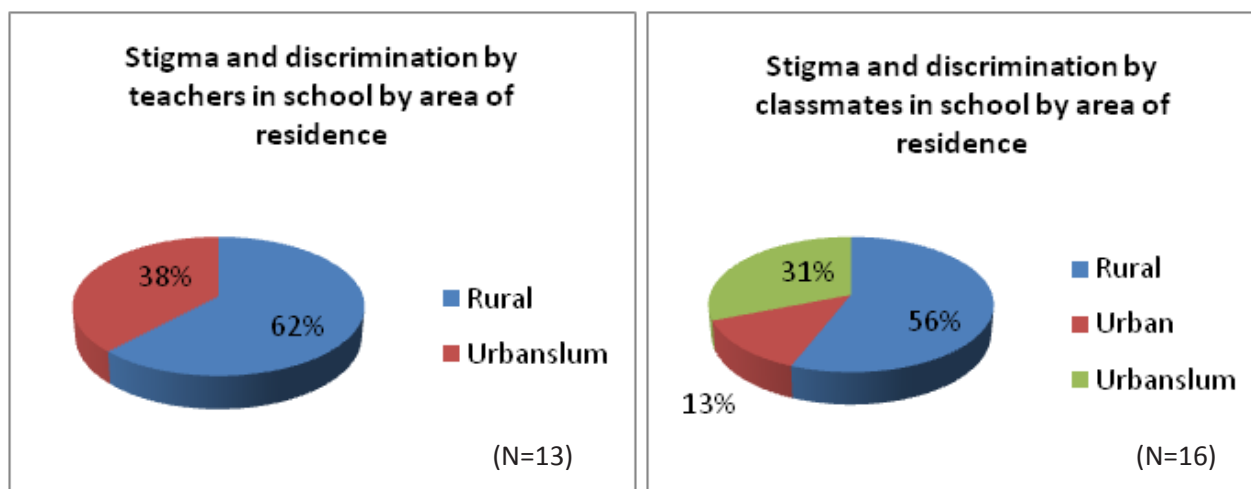
*“These children go for higher education but school/college fees are a big issue. Guardians somehow manage for the first two years but it becomes difficult afterwards. What do they do in such a scenario.... stop the studies in between? These children (orphans) are generally staying with relatives. If there is no earning member in the family, then it’s a big problem. The care givers of these orphaned children have their own family....their own children to look after. It (caring for the orphans) means double expenses for the care giver. Many a times these children (CABA) are single orphans or double orphans. We haven’t seen older children having both parents.”*

(FGD participants from Sangli, female)

*Stigma and discrimination in schools –*

HIV status of parents / children was known to teachers in only 12% of the cases. Denial of school admission due to HIV status was reported by a few care givers (n=2). Majority of care givers had not disclosed the HIV status in school. Twenty-nine participants reported discrimination in the school; either by the teachers (n=13) or by the school mates (n=16). Sixteen children were single orphan and 3 were double orphans. All of these children stayed in rural areas or urban slums except two, who reported stigma from peers. There were no district-specific differences. As told by the representatives of the organizations, there is hardly any communication between the child and caregivers on the issue of HIV in general. It is therefore likely that stigma and discrimination faced by the children remains under-reported.

**Figure 9 : Stigma and discrimination in school by area of residence**



*“The other children in the school used to tease my kid by saying that “your father had this disease (HIV)”. They (my kid) got tired of continuous taunting and stopped going to school. I, and his uncle-aunt explained to him. After that he started going to school”.*

(39 year old woman, widow, Mother of 13 year old HIV-affected boy)

*“Children get food (mid-day meal) in the school. They are asked to wash the utensils in which they eat. These utensils are kept separately and are marked by a red marker”*

(65 year old woman, `Grandmother of 6 years old HIV-infected girl and 7 years old HIV-infected boy)

*“PT (Physical Training) teacher does not allow my kids to touch toys or sports equipment.”*

(38 year old woman, mother of 8- and 13-year old boys who are HIV-affected, and infected respectively)

*“The school teacher once told her (my grandchild) to sit in the last row (of the classroom), behind everybody. She came back home. Later I visited the school and talked with the teachers. After that she never got such kind of treatment.”*

(60 year old woman, grandmother of 10 year old HIV-infected girl)

The child may lose interest in studies due to stigma and discrimination, and the burden of secrecy about HIV status. Many a times these children do not know their own, or parent’s HIV status. In such a situation, discriminatory behavior or remarks by other people can raise several questions for the child. Lack of space to discuss these issues with parents or teachers can further affect their coping with the situation.

As informed by one of the service managers, levels of stigma in schools appear to have reduced. All schools are given specific directives regarding non-discrimination. There have been some initiatives in the past to sensitize school teachers about issues of HIV/AIDS; however there are gaps in implementation of these programs. It is challenging to conduct training for private schools as they show little interest in such activities. Officials from the Education Department were unaware of any incidents of stigma and discrimination in schools. We could not get any information about specific/formal mechanisms to identify and address such incidents.

*Type of school and medium of education (Table 10) -*

In this cohort of HIV-infected and affected children, almost 44% were attending private school. The proportion was higher in HIV-affected children (51%) than infected (38%), and in urban population (70%) and slum-based children (49 %) compared to rural (32%) children. Proportion of children going to private school remained above 40% across all economic categories and all districts. Perceived poor quality of education in government schools and peer pressure to put the child in a ‘good’ (private) school was likely to be a major reason behind this. However it also meant further drain on an already over-stretched household budget. Almost 60% parents had borrowed money to meet education-specific requirements.

**Table 10 : Type of school and medium of education**

	<b>HIV Affected N (%)</b>	<b>HIV Infected N (%)</b>	<b>Total N (%)</b>
<b>Type of school (n=477)</b>			
Government	122 (50)	143 (62)	265 (56)
Private	126 (50)	86 (38)	212 (44)
<b>Medium of education (n=473)</b>			
Marathi	158 (64)	164 (72)	322 (68)
English or semi-English	73 (30)	42 (18)	115 (24)
Other	14 (6)	22 (10)	36 (8)

*Need for assistance for education -*

Care givers and organizations spelt out the need for assistance for the education of children. To some extent assistance from social welfare schemes helped in meeting education needs of the children, but this was not adequate.

The existing psycho-social services for CABA do not focus on education. Counseling at ART centers revolves mainly around issues related to HIV testing of the child and ART adherence. Many organizations currently working for PLHA and CABA do not have a mandate to work on the educational needs of children.

*“Till date we were working for HIV-related issues only with respect to health. For the first time we have started working on education of these children. If the child is out of school after 7th-8th*

standard for about 3-4 months we try to readmit the child in the school. But they are unwilling to go back to school. We say that these children are not interested in studies so we leave it. But now I feel that the real reasons for not going to school are not understood by us. Now I know that the real reasons could be different..... may be child is discriminated in school, plus the other problems that the child is facing,..... that's why s/he does not want to go to school.”

(FGD participants from Pune, male)

### Illness burden and health care seeking

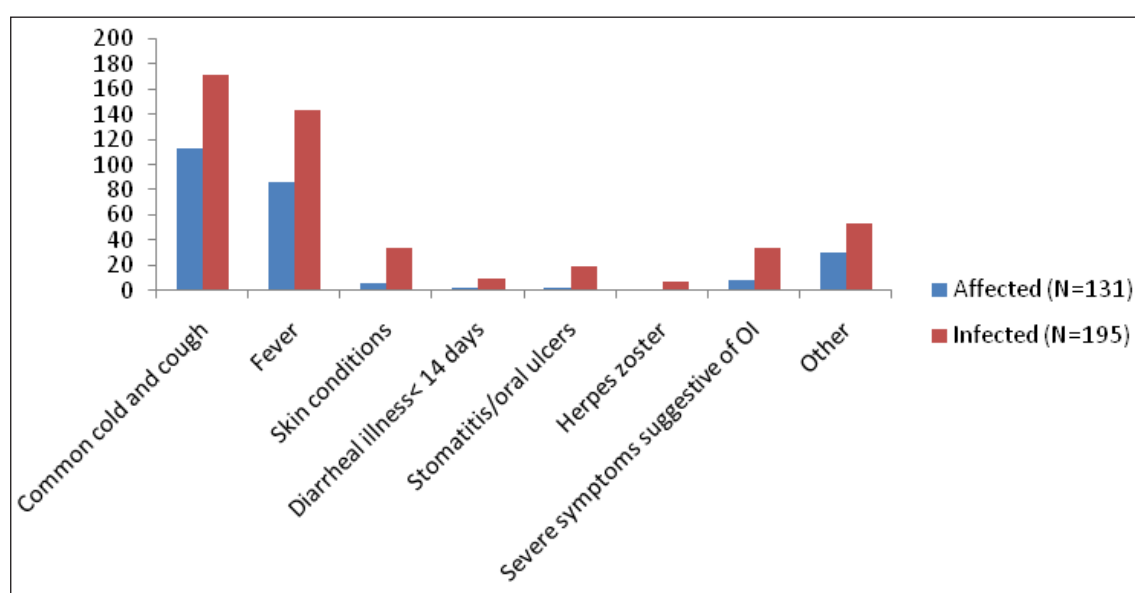
*Illness burden and treatment seeking – (Table 11)*

Care givers were asked whether the child was sick anytime during the last 3 months, and the type of facility where medical care was sought. Around 64 % of the children had fallen sick during the last 3 months. This proportion was higher for HIV-infected children (75%) compared to HIV-affected (52%) ones. Common cold, cough, and fever were the most common complaints in both the groups (Figure 10). Almost 20% of the HIV-infected children had signs/symptoms suggestive of opportunistic infections.

**Table 11 : Burden of illness among HIV infected and affected children and treatment seeking**

	HIV-Affected N (%)	HIV-Infected N (%)	Total N (%)
<b>History of illness during last 3 months (n=510)</b>			
Yes	131 (52)	195 (76)	326 (64)
no	121 (48)	63 (24)	184 (36)
<b>Treatment sought for the illness (n=326)</b>			
Yes	124 (95)	191 (98)	315 (97)
No	7 (5)	4 (2)	11 (3)

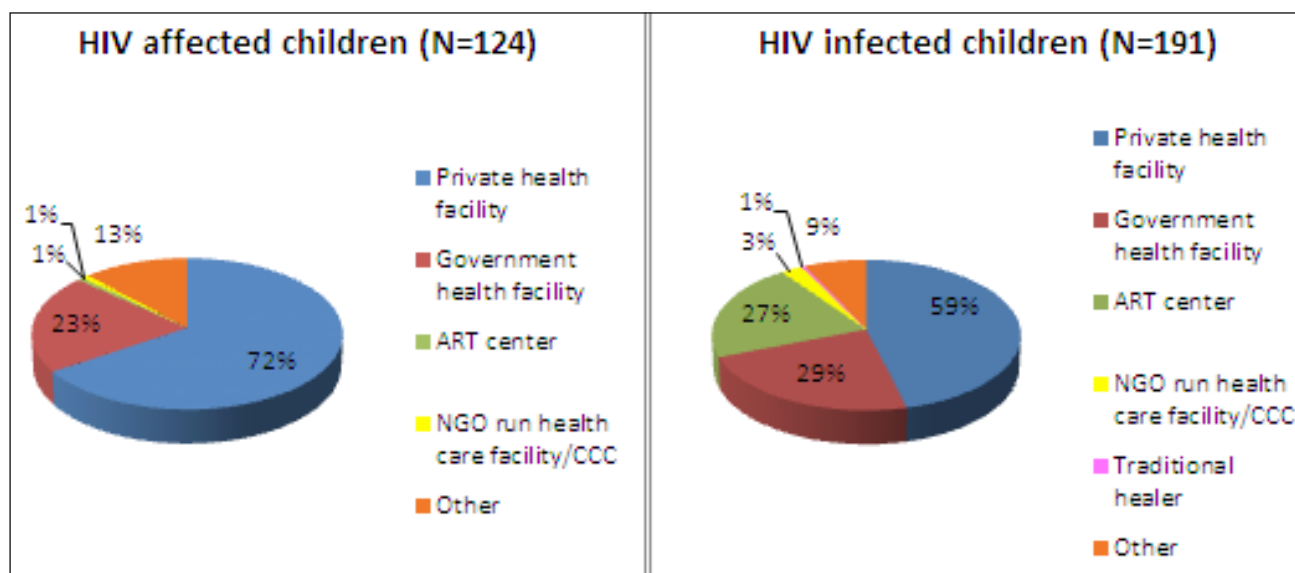
**Figure 10 : Commonly reported illnesses during last three months**



(Severe symptoms suggestive of OI includes fever > 1 month, blurred vision, diarrhea > 14 days, cough > 2 weeks, severe headache with vomiting. Other symptoms include headache, acidity, body aches, tonsils etc)

Medical care was sought for the majority of illnesses (96%). There were no major differences in treatment-seeking based on HIV status, gender, or area of residence. In case of HIV-affected children treatment was sought more at private health facilities (65%). For HIV-infected children treatment was sought equally in government and private sector. ART center was an important option for this group. (Figure 11)

**Figure 11 : Type of facility where treatment was sought for the illness during last 3 months**



(‘Other’ includes – ‘medicines bought at medical shop’, ‘home remedies’)

*Hospitalization of children (Table 12) –*

Almost half (45 %) of the children were ever hospitalized. A median of 2 (IQR – 1 to 2) and 1(IQR-1) hospital event/s were seen in HIV-infected and affected children respectively. This accounted for a median of 10 days (IQR – 5 to 17 days) and 5 days (IQR – 3 to 8 days) of hospitalization in the respective groups.

The proportion of hospitalization during last year was 3 times higher in HIV-infected children (25%) compared to affected children (8%). Among HIV-infected children, the burden of hospitalization remained high irrespective of ART status; 27% in children taking ART and 19.6% in those not on ART. In more than half the cases the expenses were met by borrowing money or selling household assets/ gold, or taking a loan. Around 52% of most of the recent hospitalizations were in a government facility.

**Table 12 : Details of hospitalization of children by HIV status of the child**

	HIV-affected N (%)	HIV-infected N (%)	Total N (%)
<b>Ever hospitalized (n=510)</b>			
Yes	77 (31)	156 (60)	233 (46)
No	175 (69)	102 (40)	277 (54)
<b>Hospitalized during last year (n=510)</b>			
Yes	21 (8)	65 (25)	86 (17)
No	231 (92)	193 (75)	424 (83)

Type of facility during most recent hospitalization(n=198)			
Government	22 (36.6)	81 (58.7)	103 (52)
Private	37 (61.7)	54 (39.2)	91 (46)
Don't know	1 (1.7)	3 (2.1)	4 (2)

Even though treatment was free of cost in government hospitals, expenses for medicines, investigations and other costs were burdensome. Relatively less number of care givers (4%) reported stigma or discrimination during hospitalization.

*“In the government hospital, there was no cost for the treatment. But we had to buy all the medicines from outside. We spent lot of money on that. At times, people donated some money. Government hospital provides for food for the admitted patient. But she (girl child) was not eating that.”*

(40 year old woman, widow, mother of 17 year old HIV-infected girl)

#### *Access to HIV care and support services–*

The median age for HIV testing was 6 years (IQR - 2-9 years) among these children. In 82 % cases, testing was done at a government facility. The proportion of children not tested for HIV was higher among unlinked (9%) compared to linked participants (3%).

Diagnosis of parents was the most common reason for testing children. The median time-lag from diagnosis of the index case in the family to the diagnosis of child was one year (IQR – 0 - 3 years).

All HIV-infected children were enrolled at an ART center. However this 100% linkage to ART centers may be due to sampling bias, as the sample was drawn from NGOs facilitating linkage to HIV-care services.

Majority (97%) were enrolled at government ART centers. A total of 197 children (76%) were started on ART medicines at a median age of 9 years (IQR - 6-12 years). They were on ART for a median of 3 years (IQR- 1-6 years). The proportion of children taking ART among linked and unlinked participants was 77% and 74% respectively. Around 3.5% children taking ART had not visited the ART center in last 3 months. Of those who were in pre-ART stage (n=61), 23% had not visited the ART center in last 6 months. (Table 13)

**Table 13 : Access to HIV care and support services**

	Infected N (%)
<b>Type of HIV care facility (n=258)</b>	
Government	250 (97)
Private	8 (3)
<b>Child on ART (n=258)</b>	
Yes	197 (76)
No	61 (24)
<b>Child not on ART and visited ART center at least once during last 6 months (n=61)</b>	
Yes	47 (77)
No	14 (23)
<b>Child on ART and visited ART center at least once during last 3 months (n=197)</b>	
Yes	190 (96)
No	7 (4)

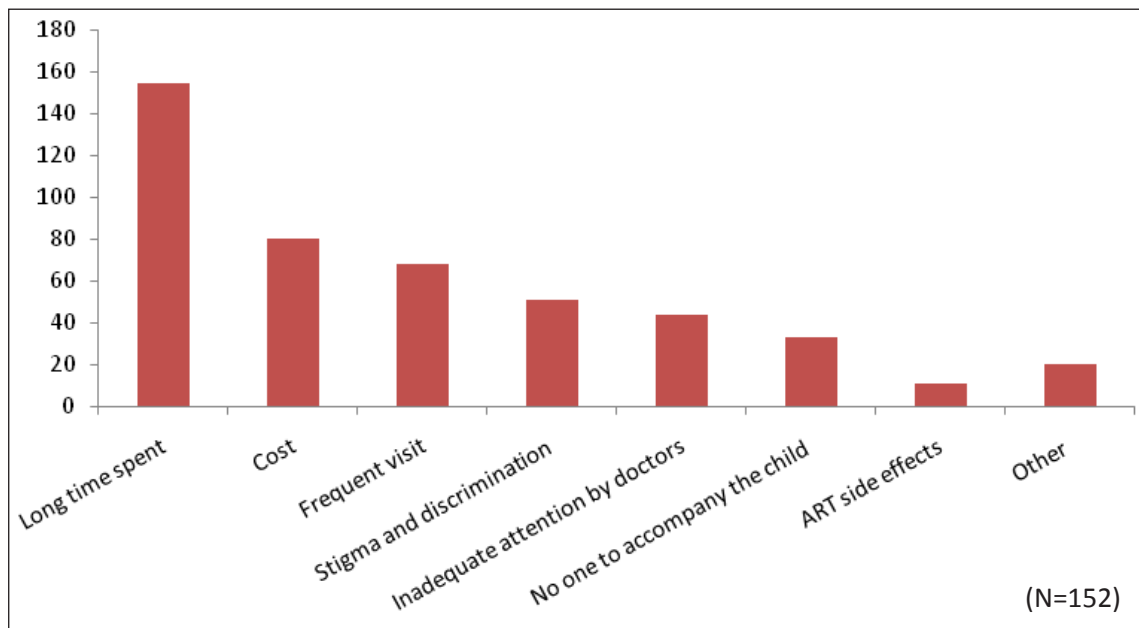


The most frequent difficulty faced by the participants were long wait in ART center (54%), cost of each visit (53%) and long time required to reach the center (39%). (Figure 12). The long wait and frequent visits to ART center meant loss of wages for the care givers. Overlapping timing of school and ART OPD resulted in school absenteeism as well as ‘no show’ at ART center.

*“I don’t take the child to ART center always, cannot skip school so many times. One cannot give a different reason every-time for skipping school.”*

(33 year old woman, Step mother of 15 year old HIV-infected boy)

**Figure 12 : Difficulties faced by care givers in accessing care at ART center**



*‘Other’ includes- no energy to go, illness, can’t take leave from school.*

#### *Nutritional supplementations –*

Nutrition is an important aspect of treatment of HIV-infected children. Nutritional requirement of these children is very high. The need for structured and reliable interventions for nutritional supplement to children came up strongly during FGDs. However, several barriers were identified in provision of such supplementation. Some of the organizations provided such supplements on a project basis and thus could provide support only for a short duration depending on availability of funds. The nutrition supplements provided to the child often got distributed in the entire family, and thus the objective of the support was not served. Currently double ration is provided to HIV-infected children through ICDS. However this scheme is restricted to children below 6 years.

*Access to psycho-social support (counseling services) -*

The psycho-social burden caused by HIV among adults has been amply documented. This could become even more exaggerated for adolescents living with HIV (ALHIV) transitioning to adulthood. Issues such as disclosure (knowing one's own/parent's HIV status), concerns related to health, sexuality, friendship, marriage, peer pressures, stigma and discrimination, parent's illness/death, insecurity about future, etc., can adversely affect their mental health and therefore need attention. The issue has not been adequately addressed by health care systems.

Disclosure is the first step in coping with the situation. Age-appropriate disclosure is almost non-existent. Disclosure is delayed to the point where it is almost no more possible to delay it further. This must be affecting the wellbeing of the children. Care givers, counselors at ART centers as well as the staff of CBO/ networks/ NGOs are not adequately trained or equipped to handle intricate issues of child counseling and disclosure to the child.

*"My son gets bored to go to Civil hospital. He asks too many questions when we go to ART center. So I did not take him to the center."*

(31 year old separated woman, mother of 13 year old HIV-infected boy)

*"My kids are growing up. I can't talk with them about things related to sexuality. And both the children are positive. They give lot of trouble, don't take ART, or take it irregularly."*

(42 year old woman, widow, mother of 15 and 17 year old HIV-infected boys)

Most of the organizations had their primary focus on provision of assistance (monetary, or in kind-supplies, nutrition) or ensuring linkage to ART care and prevention of loss to follow up. It is likely that many of the specific psycho-social needs of HIV-affected and infected children remain unnoticed and unaddressed. A few organizations from Pune and Mumbai have designed specific strategies for HIV-infected children to address issues of disclosure and the needs of growing up. However use of these strategies remains restricted to the clientele linked to those particular organizations.

Pediatric counseling services at ART centers were perceived to be inadequate. It was felt that counselor could not give sufficient time for each child considering the burden of service provision at the ART centers.

*"At ART centers, effective counseling for children above 12 years is completely lacking."*

(FGD participant from Solapur, man)

*"Number of People coming at ART center is huge hence giving time for counseling of each child is not possible."*

(FGD participant from Sangli, woman)

A dedicated team of health care providers is present only at the Center of Excellence for pediatric HIV care. This center at *Lokmanya Tilak Municipal General Hospital (Sion)*, Mumbai, has adopted many strategies to address the needs of these children. For example, separate days allocated for new, and follow-up cases have distributed the work load evenly. Health care providers can there by prioritize and spend more time for the neediest cases. Focused efforts are taken to improve disclosure to children and facilitate peer support for them. However such initiatives seem to be lacking at peripheral ART/ Link ART centers. MSACS has recently initiated 'telemedicine support' through which health care providers are provided guidance on difficult cases during periodic 'video counseling sessions'. The aim of this initiative is to increase capacities of health care providers as well as to directly reach out to patients. But there still remains the need for hands-on training.

“ORW has so many tasks to do. They cannot do child counseling. We need help of experts (to do child counseling) but it is not available.”

(FGD participant from Solapur, man)

### Access to child protection services

Birth certificates were not available for about 4.5% children. The proportion was higher among girls (5.3%) compared to boys (3.8%); and among children living in urban slums (6.4%) compared to urban (5.4%) or rural (3%) areas, A high proportion of children from Solapur (10%) and Mumbai (6.6%) did not have a birth certificate. Child’s name was included in the ration card in 80% cases. In 12% of cases, children’s names were not on the family ration card. In case of 8% children, care givers did not possess ration card. These were mostly widowed/divorced/separated women.

### Right to property –

One third of care givers did not have any property (28.3%). This proportion was higher among women (38%).

Sixty three percent care givers had either self-earned property or an inherited one. In the majority of cases it was inherited property (81%).

Among children with at least one parent alive, grandparents (60%) followed by parents (30%) had the property in their names. Among double orphans, after the grandparents (64%), ‘uncles’ (16%) were the second most important relation who had the property in their name. In only 63 cases, care givers had nominated the child for rights in the property. (Table 14)

**Table 14 : Relation with the child of the person currently holding rights for the property**

Relation with the child	Both parents alive N (%)	Single parent alive N (%)	Both parents expired N (%)	Total N (%)
Father	44 (35)	11 (7)	2 (77)	57 (18)
Mother	3 (2)	34 (22)	0 (0)	37 (12)
Grandparent	77 (61)	96 (62)	20 (67)	193 (62)
Both parents	0 (0)	1 (0.7)	1 (3)	2 (0.6)
Child him-/herself	0 (0)	4 (2.6)	1 (3)	5 (1.8)
Uncle	3 (2)	8 (5)	5 (17)	16 (5)
Other	0 (0)	1 (0.7)	1 (3)	2 (0.6)
Total	127 (41)	155 (50)	30 (9)	312 (100)

Qualitative data showed that many widows and separated women were disowned by the in-laws. In some cases, these women did not possess basic documents such as ration card.

“I don’t have my own house. My mother-in-law does not give me the house. My husband committed suicide by taking poison. Mother-in-law blames me for the death of my husband. She says ‘he (my husband) could not bear that you have such a disease (AIDS). We cannot show our face to the society because of you’.”

(30 year old woman, widow, mother of 11 year old HIV-affected girl and 14 year old HIV-affected boy)

*“My brother- in-law has disconnected electric supply of the house where I am staying. He does not want me to stay there.”*

(43 year old woman, widow, mother of 8 year old HIV-infected boy)

Interpretation of the qualitative data in the light of indicators from the quantitative data points towards a possibility of property rights violations by paternal relatives of children after death of parents. During FGDs organization representatives shared some examples of manipulations done in the property records so that child and parents are denied of their rights in the inherited property. Such manipulations were possibly done with the knowledge and/or assistance of administrative officials.

*“We had a case where the parents of the girl child passed away and grandmother was taking care of the child. Her (child’s) uncle-auntie said that her (child’s) share of the money was spent on the illness of her parents. So after the death of her father they made new property document in which they put names of other two uncles. So now, no one can intervene for the rights of the girl.”*

(FGD participant from Sangli, woman)

*“Some people have deleted names (of children) from ration card. Parents name was there on the ration card, but after the death of parents name of the child was deleted from ration card.”*

(FGD participant from Sangli, woman)

Lack of availability of necessary documents posed difficulties for organizations to put up legal cases on the child’s behalf. In case of double orphans, if guardian/custodian of child was the one trying to muzzle the property then the matter was even more difficult to handle. An orphan in custody of such care giver would be unable to raise objections. Even though an organization was aware of the situation, there was little room left for corrective measures.

*“If the parents think before, during the critical condition, there are very high chances of child getting the rights. If parents don’t think, caregiver (other family members) can take (dis) advantage. Even though the child is aware....that caregiver is using his/her money still he/she can’t say anything. Even we (organization) can’t say anything. “*

(FGD participant from Mumbai, man)

At the time of this assessment, most of the organizations were not actively intervening for timely nomination of the children on the property cards. There were a few reports from Mumbai of successful intervention by legal-aid cells and NGOs providing legal support. However in rest of the districts, there were very few referrals to legal-aid cells.

#### *Stigma and discrimination by family members -*

There were several examples where, after the death of the husband, the wife and children were thrown out of the house by the in-laws. Distancing by other relatives was commonly seen. In general, maternal family (especially grandparents) was supportive and played a major role in looking after single and double orphans.

### *Felt need for institutionalization -*

Thirty one percent care givers reported that they wanted the child to be institutionalized. Financial constraints (71%), need for further education of the children (62%) and lack of physical help in the household (39%) were the important reasons. This need was heightened in cases of widowed/divorced/separated care givers. There was no difference across economic category of the care provider.

Single parent with/without grandparents was the primary care giver in a large number of children. In such a situation care givers were concerned about who would look after the child after their death. This fear, along with other constraints, intensified the urge to keep the child in an institution.

*“Right now I am staying at my mother’s place. I am not sure if my brothers will look after my child after my death. So I feel I should keep the child in an institution”*

(35 year old woman, widow, mother of 14 year old HIV-infected child)

*“I think of keeping the children in institution because of financial constraints and I feel there has to be someone to look after the child after my death. Their (children’s) grandparents are old. They (grandparents) won’t be able to earn, so I feel like keeping the children in institution.”*

(41 year old woman, widow, mother of 11- and 14-year old affected children)

Only 13 care givers had sought help from child welfare committees (CWC) for alternative care for the child (eg. foster care or institutionalization). Except for Mumbai, the experience of CWC in relocating the children was not very encouraging. The situation of residential hostel facilities was reported to be poor. Institutionalizing HIV-infected children was challenging as many children’s homes denied admission to these children. The state of Maharashtra has 36 districts. All except 3, are categorized as high-prevalence districts. At the time of assessment, there were only 18 registered children’s homes which cared for CABA (Appendix 4). There is a complete lack of these facilities in regions such as eastern Maharashtra and tribal districts.

### *Safety of children from sexual abuse*

A quarter of the care givers reported safety concerns for the child. They had heightened concerns for girls. Strangers (48%) and older boys (35%) were perceived as ‘risk’ by many in this regard. Around 24% reported that the child was at risk from ‘everyone’. They thought that police (58.5%), relatives (25%) and institutions (21%) were likely places from where help would be sought in case of any untoward incident.

### **Access to social welfare schemes**

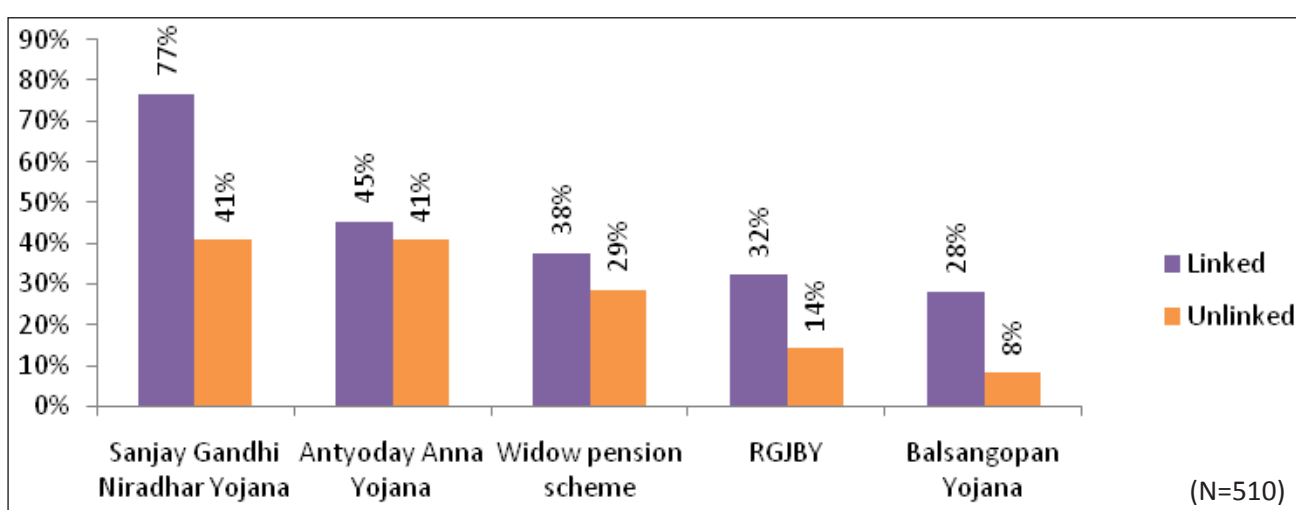
#### *Awareness about social benefit schemes -*

The proportion of care givers who had heard of social benefit schemes was as follows - *Sanjay Gandhi Niradhar Yojana (70%), Antyodaya Anna Yojana (44%), Widow pension scheme (36%), Rajeev Gandhi Jeevodaya Bima Yojana (RGJBY) (29%), BalSangopan Yojana (24%,).* (Table 15). The unawareness about schemes was very high among people not associated with any organization. (Figure 13).

**Table 15 : Awareness about social benefits schemes among care givers**

Scheme	Care givers who had heard of the scheme	
	N	%
Sanjay Gandhi Niradhar Yojana	356	69.8
Antyodaya Anna Yojana	227	44.5
Widow Pension Scheme	183	35.8
Rajiv Gandhi Jeevodayee Bima Yojana	147	28.8
Bal Sangopan Yojana	124	24.3

**Figure 13 : Awareness about the social benefit schemes among care givers by linkage to organization**

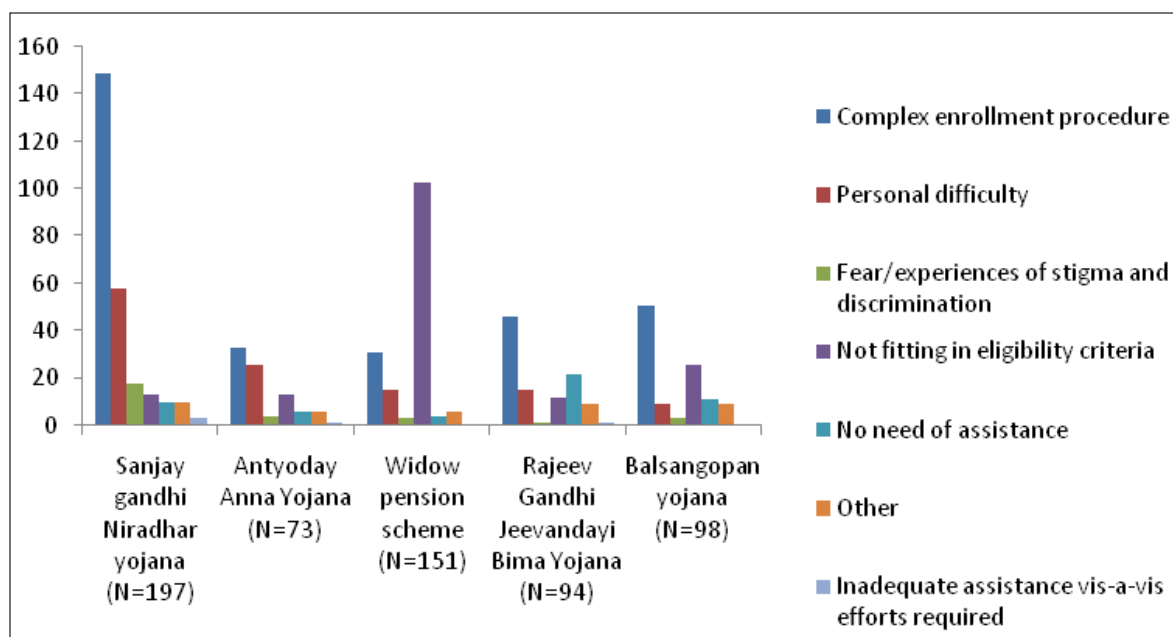


*Barriers to access the schemes –*

Except for *Sanjay Gandhi Niradhar Yojana*, the overall awareness about other social benefit schemes was low. Even among those who were aware, several barriers to access the scheme were noted.

Complex registration procedures (large number of documents required, frequent visits to multiple offices), lack of information about the procedures were important reasons for not accessing the scheme. (Figure 14). Many could not access the benefit due to personal/household level barriers (such as lack of required documents, no time to collect documents, could not afford to pay for travel/paperwork, or lose wages). There were complaints regarding corruption by the officials, and exploitation by agents (middlemen). These difficulties were further intensified due to additional household responsibilities due to high burden of illness in the family.

**Figure 14 : Reasons for not accessing the social benefit schemes**



Stigma to HIV was another barrier that further limited access of PLHA to social benefit schemes. Some of the care givers did not initiate the process of registration for the scheme as they were unwilling to disclose their HIV status to *Talathi/Tehsildar* office. They feared uncontrolled disclosure of their HIV status in their community.

*“Municipal corporation employee said that when you earn this much how can I give you certificate that you earn rupees 12 thousand. He does not know (the situation). And there are 17 other people with him so how can I tell (disclose HIV status).”*

(FGD participant from Mumbai,man)

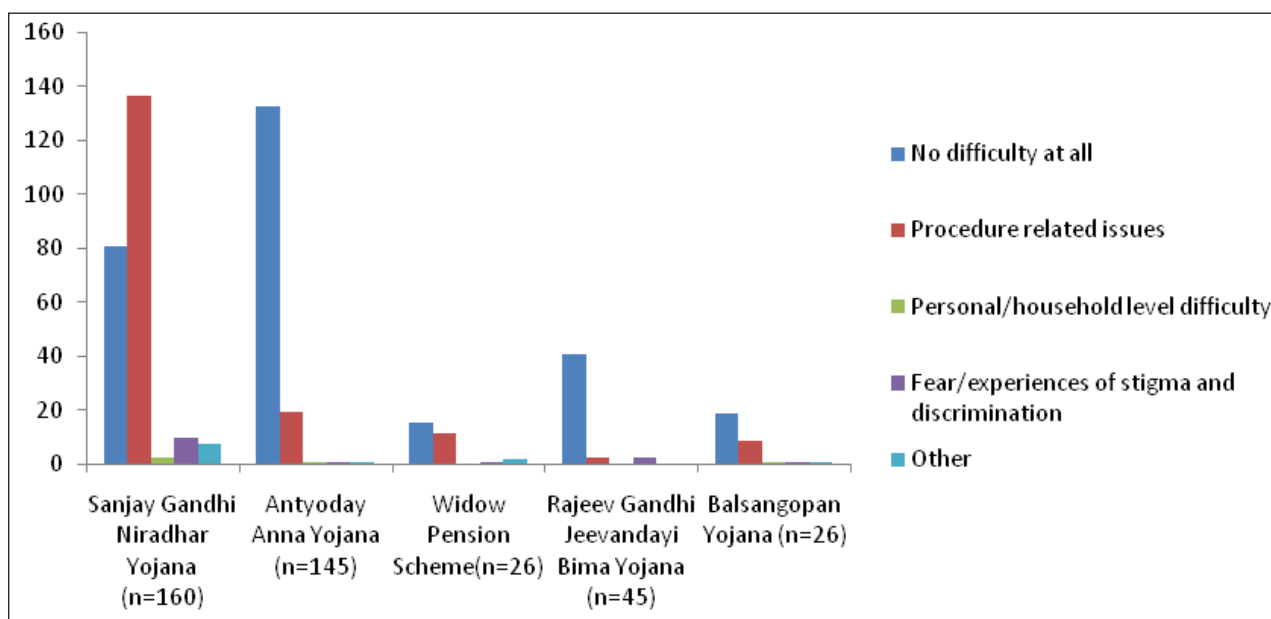
#### *Uptake of social benefit schemes -*

We could not check the eligibility status of the participants for social benefit schemes. During the interviews we asked about the number of participants availing of the schemes and difficulties faced while doing so. Of the total 510 care givers, *Sanjay Gandhi Niradhar Yojana* (n=161) / *Widow Pension Scheme* (n=27), *Antyoday Anna Yojana* (n=152) were commonly accessed across all districts (Table 16). Only 25 children were linked to *BalSangopan Yojana*. (Figure 15). Among these people, procedure-related issues were the only major difficulty faced while registering. FGD participants reported a few discriminatory practices such as noting down HIV status on ration card, mention of disease on confirmation of registration letter sent to the household, etc.

**Table 16 : Uptake of social benefit schemes among care givers**

Name of the Scheme	Care givers who were accessing social benefit scheme (n)
Sanjay Gandhi Niradhar Yojana	161
Antyodaya Anna Yojana	152
Widow Pension Scheme	27
Rajiv Gandhi Jeevandayee Bima Yojana	53
Balsangopan Yojana	25

**Figure 15 : Difficulties faced while registering for the social benefit schemes**



The objective of *Bal Sangopan Yojana* is to provide home-based care in biological family or alternative family through financial assistance for 0-18 year old children who are orphans, destitute or in a crisis situation. The October 2013 Government Resolution (GR) states ‘CABA’ as one of the eligibility criteria. It does not mention whether the child needs to be in school in order to access the benefit. However during the FGDs, participants noted that school drop-outs were told to be non-eligible for the scheme. These children were also not eligible for *Sanjay Gandhi Niradhar Yojana* because of the age criteria. Parents as well as organizations raised the issue of the need of financial assistance for education of these children. It was felt that this would be especially helpful for orphans.

*“There are a few such children who are below 18 years that are looked after by grandparents. Because of their age these children are not eligible for Sanjay Gandhi Niradhar Yojana. If they are not going to school, they don’t get Balsangopan Yojana as it is for the educational support of the children.”*

(FGD participant from Sangli, man)

## Gender Dimensions

The assessment highlights gender dimensions of the HIV/AIDS epidemic that puts women at a higher disadvantage. In a large number of households (n=271), children were looked after by single mother. In 163 cases, mother was the only care giver in the family. In 108 cases mother was helped by other family member/s; mostly her parents.

Profile of these women indicates multiple factors that add up and increase their vulnerability. All of these women were widowed, divorced or separated. Almost all were HIV-infected. Around 69% of them were working as unskilled worker, 11% were not employed; 20% were illiterate and 35% had completed pre-primary/primary education. The majority (84%) belonged to the lower economic status.

Although majority of the women were linked to the organizations, their awareness about the social benefit schemes was poor. The following proportion of women had heard of various social welfare



schemes - *Sanjay Gandhi Niradhar Yojana* (77%), *Widow Pension Scheme* (40%), *Balsangopan Yojana* (26%). Only 151 and 15 were availing of the *Sanjay Gandhi Niradhar Yojana/Widow Pension Scheme*, and *Balsangopan Yojana* respectively.

These women were vulnerable to get stigmatized and discriminated by their in-laws, removed from the in-law's house, and disowned of their rightful property. Of the 169 women who had some property (either self-earned/inherited), only a few (n=32) had their name on the property card. The government has set up systems such as free legal-aid cells, to help these women fighting for their rights. However awareness among these women about the support systems was poor. Only 24 women had heard of free legal aid available in the district. Even if the woman is aware of her legal rights and free legal aid, fighting for these rights is extremely difficult. If she is staying with paternal family these fights are likely to invite further domestic violence and withdrawal of the already meager support. If staying with her parental family, the family may not be keen to initiate or join the battle as it is already burdened with caring for the lady who has been disowned by her in-laws. If alone, property rights may not even be a priority for her while managing the basic day-to-day necessities.

Mother being a female sex worker (FSW) adds one more layer to vulnerability. Qualitative data suggests that lack of documents, and severe stigma and discrimination by mainstream society as well as service sector are major barriers to access services for this group. Children of FSW are more likely to be forced into, or engage in behaviors that accentuate their risk of acquiring HIV.

### **Efforts by organizations in linking the children to services, and barriers faced**

Several organizations working on issues of CABA participated in this assessment. Majority of them were community-based organizations or networks of positive people. The outreach of these organizations and approach to tackle the issues varied widely. Different services were offered by these organizations, such as provision of or linkage to psycho-social care and support through home-based services, provision of nutritional or educational support, provision of medical and counseling care, and provision of temporary shelter for children in crisis, etc.

These organizations faced several challenges while linking CABA to these services. These were both from the beneficiaries as well as from the service providers. Poor-quality or complete lack of services, target-oriented approach of government officials, and need for prolonged follow-up with service sector was reported. Apathy or inability of their clients (beneficiaries) to fight for their right to avail of the services made collective action or advocacy quite challenging. Excessive dependence of beneficiaries on the organizations and undue expectations were difficult to tackle. Most of the organizations, especially those aided by government, functioned on shoe-string budgets; and many reported inability even to pay salaries to the staff on time because of delays in disbursement of funds.

### **Innovative practices used by the organizations**

Many innovative strategies were adopted by the organizations in response to barriers faced in linking the children to the services. Following is a brief overview of some such initiatives.

#### *Ensuring family-based care and property rights of children –*

An organization from Mumbai (Committed Communities Development Trust, Mumbai) that provides home-based care and support for children and affected families has adopted a preventive strategy to protect property rights of the children. During initial home-based counseling sessions with the family, parents are counseled about the importance of family care. They are asked to identify relative/s to

whom HIV status of parent/child has been disclosed and who would look after the child in case of any crisis situation in the family. Parents are encouraged to nominate the child on the property card.

#### *Addressing psycho-social needs of children –*

An organization from Pune (Prayas, Pune) addresses transitioning needs of HIV-infected adolescents through structured residential workshops for adolescents with HIV. The workshops deal with several issues such as HIV disease and treatment, friendships, marriage, sexual and reproductive health, disclosure to partner and peers, and stress management, etc. It provides children the space to share concerns and draw support from peers. This has also led to formation of a peer-support group, which is now active for more than 3 years.

One of the organizations from Mumbai (Committed Communities Development Trust, Mumbai) facilitates monthly meetings which are attended by a large number of parents and children. Opinions of parents and children are encouraged from all clients prior to the meetings. During meetings, representatives of both groups (parents and children) debate different points of views for a particular topic. This helps both the sides understand each other's concerns, needs and perspectives.

#### *Facilitating linkage to social welfare schemes –*

One of the organizations in Sangli (Sangram, Sangli) has facilitated face-to-face interaction of children and the District Collector. The direct interaction provides a platform where children can raise their voice regarding challenges in accessing various services. It also helped in sensitizing administrative officials about the issues of HIV-affected and infected children.

### **Provision of services: Availability, barriers faced, and strategies adopted**

This section describes some of the key strategies adopted by the service departments, as noted by the service managers, to reach out to the beneficiaries and challenges faced. Appendix 1 to 4 provides district-specific information on availability of services for HIV care and support, education, health, and children's homes in the state of Maharashtra.

District AIDS Prevention and Control Unit (DAPCU) is the central body that monitors the HIV program in the district and coordinates with other departments to facilitate linkages to other services (such as education, nutrition, social welfare, etc.). Interaction of the District Program Officer (DPO) and community (represented by civil organizations) is facilitated through a platform such as District AIDS Prevention & Control Committee (DAPCC) meetings. These meetings are also attended by officials of other departments as per the need.

Currently HIV testing facilities are available at the periphery through Integrated Counseling and Testing Centers (ICTCs). There has been an increased focus on provider-initiated testing to encourage early diagnosis of HIV infection among children. In an attempt to increase the outreach of the services, link ART centers have been established at district/sub-district level. The state has one Center of Excellence for pediatric HIV care. The center has a dedicated team of doctors, HIV counselors and nutritional counselors to cater to pediatric patients. It also provides technical assistance and training to health care providers from ART or link ART centers. Special child counselor or specific efforts to address issues of disclosure have not yet been implemented at the peripheral centers. More recently there have been efforts to increase capacities of health care providers and to increase demand generation through telemedicine support (video counseling).

Linkage of children diagnosed with HIV, and retention in care was reported as an important challenge by the service managers. One of the reasons for this could be the relatively less number of centers with co-located ICTC and ART care. Accompanied referral to ART centers is encouraged to avoid this. ‘Lost to follow-up’ (LFU) among children enrolled at ART centers is a concern. DAPCU has collaborated with local NGOs/CBOs/networks to track these LFU cases. However tracking is difficult because of migration and wrong addresses.

Relatively small numbers of HIV-affected children has made advocacy with other departments a difficult task.

Complex documentation was identified as an important barrier to link PLHA to social welfare schemes. To improve linkages, DAPCU shares list of eligible candidates with the District Collector’s office. Camps are arranged, bringing beneficiaries and concerned officials (*talathi/tehsildar*, etc.) together, to facilitate faster processing of documents. However there was no feedback by revenue department on how many referred clients are linked to the schemes.

Service managers from all departments reported reduced levels of HIV-associated stigma and discrimination. School drop-out and/or school absenteeism in these children was not raised as a problem by the service managers. There appears to be no structured and continued programmatic effort to sensitize school teachers on issues faced by CABA.

Recently, Integrated Child Protection Scheme (ICPS) has been initiated which aims at building a protective environment for children in difficult circumstances, as well as other vulnerable children, through Government-Civil Society Partnership. ICPS committees were not yet functional at the time of this assessment. It appeared that the ‘*Bal Sangopan Yojana*’ functioned merely as a monthly financial assistance scheme to the family. There are only 18 aided/non-aided children’s homes that care for CABA. Anecdotal evidence suggests that some of them were currently dysfunctional.

## Conclusions and Way Forward

This section describes the salient findings of the assessment and their programmatic and policy implications.

### Setting the context

Children infected and affected by HIV are one of the most marginalized groups of children [15]. There have been a few studies from India that tried to document vulnerabilities of these children and their access to basic services such as health and education. However, all these studies were done at the time when ART was yet not widely available in the country. Those studies reported that HIV-infected households faced the adverse economic impact of HIV and high burden of illness. Children from these households had greater educational disadvantages [5] and faced severe forms of stigma and discrimination from family, neighbors, and schools [6]. However, these studies did not differentiate between vulnerabilities of children infected with HIV, and children uninfected with HIV but living in HIV-affected households.

A lot has changed since the last decade as regards availability and outreach of HIV care and support services in the country. HIV testing services have reached the sub-district level. Free ART is now widely available. As of 2014, nearly 0.1 million CLHIV were registered in HIV care at ART centers, of whom 42,015 were receiving free ART [2]. CLHIV are now surviving longer and even transitioning to adulthood. There are emerging psycho-social needs of this subgroup. If they are to contribute to themselves as well as to society as meaningful adults in future, health and education of these children is of paramount importance. As a signatory to the international convention on rights of children, the Government of India is committed to fulfill the rights and well-being of all children, including CABA. However little is known about vulnerabilities of CABA in the current context.

This situation analysis was undertaken to understand the current status of health and education among 6-18 year old family-based children infected, and affected by HIV. It also aimed at understanding barriers faced by the caregivers of these children to access existing services for health, education, nutrition, social protection, and child protection. The situation analysis was undertaken with an anticipation that such knowledge would help in strengthening efforts by government and other stakeholders to protect and promote rights of HIV-infected and affected children.

### Applicability of the findings of this assessment

The recruited sample in the current assessment was mainly drawn from lower socio-economic strata. The link between HIV and poverty is well established. The findings of the assessment, therefore, would apply to a large proportion of CABA in the state/country.

The recruitment was done by convenient sampling because of issues of confidentiality and lack of availability of comprehensive lists of CABA in these districts. However efforts were taken to achieve maximum generalizability of the findings. To get a more representative picture, we selected the participants from all organizations working in these districts. To reduce selection bias, we tried to use systematic random sampling while selecting the households at the organization level. The study was conducted in 4 districts of western Maharashtra. Compared to other districts in the state, the study districts are known to have much better health and educational infrastructure, and availability of HIV services. It is likely that children from more underdeveloped areas will have even higher levels of vulnerabilities than those seen in this assessment.

## Major findings and their implications

### *Educational vulnerabilities of HIV-infected and affected children –*

The proportion of HIV-affected children in a household was almost twice that of HIV-infected children. The overall proportion of out-of-school children in the entire cohort of 883 children was 8% (7% affected and 11% infected). This indicates that in the community there would be large numbers of both infected as well as affected children at risk of educational disadvantage. The national school drop-out study [21] among 6-13 year old children shows a state-level average drop-out of 0.82 in Maharashtra. Any direct comparisons with the general population cannot be made in the current analysis. However, in the current study cohort, the proportion of out-of-school children of same age appears to be greater (2.46) than the state average.

To achieve the best possible scientific rigor in understanding the risk factors for school drop-out, correlated data at household level were eliminated by selecting only one infected or affected child per household in the analysis. Of the 510 children, almost all were ever enrolled in school. However, 6.2% children were currently out of school. A much higher proportion of HIV-infected children (10.8%) were out-of-school compared to affected children (1.5%). A sudden and acute increase in school drop-out was observed among children aged 14-16 years (13%) and 17-18 years (23%). It is likely that the majority of children are retained in school till completion of primary education as per the 'Right to Education Act'. However the proportion of children continuing further education starts dropping rapidly thereafter. Other factors such as lower education of care giver, relation of care giver/s with the child, losing one or both parents, and illness of child adversely influenced the schooling status. Overlapping of risk factors disproportionately increased the risk of adverse educational outcomes. E.g. an older HIV-infected child looked after by only grandparents had very high chances of discontinuing education. HIV-infected children showed a greater lag in reaching age-appropriate standard.

Child's / parent's illness was the most prominent reason for gap in school or discontinuation of education among infected children. Failure in studies/disinterest in studies was another important reason reported in many infected as well as affected children. Several other reasons such as stigma/discrimination in school, cost of schooling, need to earn for the household, school being too far away were also reported.

There were only a few reports of denial of school admission due to HIV. However subtle level of stigma and discrimination in schools still exists. Most of the care givers reported that they had not disclosed HIV status of the child in school. However in small villages / close communities it is possible that the news about HIV status of the family spreads around and might result in subtle acts of discrimination.

There was interdependence of several individual, family, organization and society-level factors that affected educational outcomes of these children. In a resource constrained household where even basic necessities such as food, shelter and health are difficult to meet; education of children appears to be getting affected first.

### *Programmatic implications –*

The vulnerabilities of this group translate into large number of CABA being deprived of one of the basic rights of children. As illness burden is the most important reason affecting HIV-infected children, health-specific needs of these children should be urgently addressed.

There has to be a combined effort by all concerned stakeholders to reach out to children with overlapping vulnerabilities. As most of the parents prefer not to disclose the HIV status of the children

in school, teachers may not identify the needs of CABA lagging behind in studies. In such a situation, the role of counselors/out-reach workers (ORW) who are in close contact with the family could be crucial. Active engagement with the family or child about the schooling can lead to early identification of the problem, and possibility of linkage to appropriate support systems.

There is acute school drop-out in older CABA. It is likely that these children take up financial responsibilities (due to crisis situation in the family e.g. illness/death of parents) early. However, lack of education and skills would put severe limitations on their opportunities. There is a need to focus on skills development of these children.

The changed form of stigma and discrimination in schools warrants a change in approach on how teachers are sensitized. The challenge of including large number of private (unaided) schools in such initiatives needs special attention. The study cohort also showed a high proportion of children going to private schools. This stretches the limited household budget further. Another important programmatic issue that needs to be addressed is the widespread perception that the quality of education in public schools is worse than that in private schools.

#### *Illness burden among HIV infected/affected children and access to health care -*

The burden of illness and hospitalization in this cohort was very high. The burden was much higher in HIV-infected children, irrespective of ART status. Twenty-five percent of infected children had history of hospitalization during the previous year. A large proportion of cases sought treatment at private health care facilities. Even though treatment was free of cost in government facilities, out-of-pocket expenses for medicines, investigations and other incidentals were burdensome for the families. The majority of care givers had to borrow money to meet health care expenses, pushing them deeper into poverty. The illness burden also had direct implications on educational outcomes.

The children in this cohort were diagnosed late and probably initiated ART in late stage disease. Several difficulties such as distance needed to be travelled, long waits at ART center, travel expenses incurred, were reported for accessing ART care. Overlap of ART center timing with school timings was troublesome for children and it affected attendance at both the places. Malnutrition was also a major concern among these children. Currently CLHIV below 6 years are entitled to get double ration under ICDS scheme. School- going CLHIV are entitled to get mid-day meal. However there is no direct food supplementation scheme for older malnourished CLHIV that are out of school.

#### *Programmatic implications –*

Further research is essential to confirm the high burden of illness seen in CABA identified in this assessment and explore the reasons behind it. Strengthening of health systems and access to quality services for everyone is crucial. Support for travel to ART centers would be helpful.

Counseling services for children need to be greatly strengthened. Increasing skills of counselors for facilitating disclosure of HIV status to the child and addressing transitioning needs of HIV-infected adolescents is important. The feasibility, sustainability, and role of peer support in providing psychosocial support to adolescents infected/affected by HIV need to be evaluated.

The health needs of HIV-infected children are unique and complex. The small numbers of these children in the community and low availability of special services for them makes service delivery more challenging. Policy makers will have to consider this as we go ahead with convergence of HIV program with the general health care systems.

### *Access to Child protection and social protection services –*

Large proportions of children (61%) in the study cohort were orphans. Single mother was the predominant care giver. Profile of these women is indicative of their heightened vulnerabilities. Women and children were disowned from family property after the death of child's father. Maternal family played an important role in looking after the children. Grandparents were the only care givers for many double orphans.

Financial constraints, loss of one or both parents, parent's illness, and lack of support from extended families, stigma and discrimination put these children at a higher risk of falling out of the safety net. The state machinery does not appear to be geared for dealing with vulnerabilities and needs of these children. The current availability of children's homes that care for CABA is highly inadequate.

This assessment corroborates previous evidence on barriers faced by PLHA in accessing social benefit schemes [22]. Awareness about the schemes was low. Many caregivers lacked basic documents that were essential to access the benefits. Complex procedure for registration was a major barrier to access the social welfare benefits.

### *Programmatic implications -*

There is an urgent need to strengthen family based/community based care and support for these children. Instead of displaying information only about schemes of a particular state department, a concerted effort could be made by all agencies together to consolidate, simplify and disseminate information through all possible means. Focused efforts are needed to increase awareness about social benefit schemes. Various outlets such as ART centers should be explored through which the information can be disseminated widely. It should also be possible to hand out information regarding schemes for support for widows at the time of registration of the husband's death. Presenting this information in 'easy to understand' format and easing out of procedural complexities is essential. Currently there is no way to know the unmet need of social benefit schemes among PLHA. Setting up a formal feedback mechanism between revenue department and DAPCU would greatly help in monitoring progress.

Practices such as nominating the child in the property documents, identifying the successor who would take care of the child in the event of crisis should be promoted during counseling of the family. Overall there is low awareness in the community as such about the importance of timely nominations. There is a need to explore 'out of box' strategies to increase such awareness.

Even as programs focus on strengthening families of these children, one cannot neglect the needs of destitute and orphaned children who have no support systems.

An important observation emanating from this situation analysis is that the efforts to improve health, education and well-being of these children cannot be done in isolation of each other. Apart from providing healthcare, HIV programs in the country need to strengthen their coordination with non-health services such as education, social welfare and child protection services. Pro-active steps by all the concerned departments and combined efforts by government and non-government agencies working for the cause would play a crucial role in reducing the vulnerability and ensuring wellbeing of these children.

## Recommendations

- **Support for improving educational status of CABA -**
  - **Identifying CABA in need** - The school drop-out rates are very high (8%) among CABA. Children lagging behind in schools need to be identified and followed up closely. Counselors, and outreach workers need to be trained to be more vigilant.
  - **Referral to crisis intervention centers** - Child's illness and parent's illness/death are the most common reasons for school drop-out. Alternatives such as crisis intervention centers along the lines of *Ashray* in Mumbai, or facility of temporary substitute family care through *Bal Sangopan Yojana* could be thought of in such cases.
  - **Financial support for continuing secondary education and skills development**—There is a rapid drop-out from schools among CABA, especially above 13 years of age. Special attention will have to be given to their skills development. There is a need to provide economic support for education.
  - **Addressing stigma and discrimination at school** - Subtle level of stigma and discrimination in schools exists. Sustained efforts to inculcate 'HIV sensitive' approach in schools are needed to achieve 'zero discrimination'. The challenge of including large number of private (unaided) schools in such initiatives will need special attention.
- **Support for improving health of CLHIV –**
  - **Reducing the illness burden among CLHIV** - Late diagnosis, delayed linkage to ART care and poor retention in care increase illness burden among CLHIV. Gaps in the National program (especially PPTCT) need to be bridged.
  - **Support for health expenses** –The out-of-pocket expenses for treatment of inter-current illnesses is often met by borrowing money. This leads to increased impoverishment of the household. Improving availability of medicines at government facilities/hospitals by strengthening community-based monitoring and financial assistance in crisis situations will prevent this.
  - **Travel support for visits to ART center**-Time spent and cost of visits are common difficulties faced while accessing care at ART centers. Support for travel to ART centers needs to be rapidly rolled out.
  - **Nutritional supplementation to CLHIV** - Malnutrition is a major concern among CLHIV. The nutritional support provided is inconsistent and inadequate. There is a need for continuous and focused nutritional supplementation.
  - **Strengthening counseling services for children** - There is a need to strengthen ART centers along the lines of pediatric Centers for Excellence. More efforts are needed to build the capacities of counselors.
  - **Addressing psycho-social issues of ALHIV** - Adolescents living with HIV are likely to face severe psycho-social burden. There is a need to strengthen linkages of 'ALHIV in need' to specialty services. Opportunities of participation and empowerment of HIV infected and affected adolescents to strengthen their life skills and self-resilience have shown promising results and need to be expanded.



- **Economic support to families caring for orphaned CABA** - Most of the HIV-affected households belong to lower socio-economic strata. A large proportion of CABA are orphans. Single mother is the predominant care giver in the family. In case of orphans staying with grandparents, finances are the major constraint. These families require additional economic support.
- **Ensuring property rights of CABA** - Property rights violation of widows and orphaned children is commonly seen. Preventive strategies such as nomination of child for the property should be discussed with parents during counseling sessions.
- **Increasing awareness and accessibility to social protection schemes** - Awareness about social protection schemes is low. Procedural difficulties lead to low uptake. Consolidation, simplification and use of all available avenues to disseminate information about the schemes will definitely go a long way towards increasing uptake. This will prevent many children from falling through the safety net. Currently there is no way to know the unmet need of social benefit schemes among PLHA. Setting up a formal feedback mechanism between revenue department and DAPCU would help in monitoring the progress.
- **Increasing availability of institutional support for CABA in crisis** - In spite of all the efforts to strengthen the families, parents/guardians of CABA feel an acute need for institutionalization in extremely difficult situations. There are a large number of children homes in the state; however only a few cater to CABA. Advocacy efforts are needed to ensure that CABA can access the children's homes.

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## Appendices

### Appendix 1 – Services for HIV care and support in the state

Number of ART/Link ART centers (source –MSACS, 21<sup>st</sup> April 2015)

Sr.No	District	ART	L-ART	L-ART Plus
1	Thane	8	12	0
2	Raigad	2	11	0
3	Ratnagiri	1	6	3
4	Sindhudurga	1	4	0
5	Nashik	2	6	2
6	Dhule	2	4	0
7	Nandurbar	1	4	0
8	Jalgaon	2	10	0
9	Ahamednagar	2	13	2
10	Pune	7	19	3
11	Solapur	3	8	2
12	Satara	3	11	4
13	Kolhapur	4	7	2
14	Sangli	4	9	5
15	Aurangabad	3	5	0
16	Jalna	1	5	0
17	Parbhani	1	6	0
18	Hingoli	1	3	0
19	Latur	2	8	1
20	Osmanabad	2	6	0
21	Beed	2	7	1
22	Nanded	1	9	1
23	Akola	1	6	0
24	Washim	1	4	0
25	Amaravati	1	8	0
26	Yavatmal	2	9	0
27	Buldhana	1	5	0
28	Nagpur	3	7	3
29	Wardha	1	3	0
30	Bhandara	1	6	0
31	Gondiya	1	1	0
32	Chandrapur	3	7	0
33	Gadchiroli	0	0	0
34	Mumbai	14	0	0
	<b>Total</b>	84	229	29

## Appendix 2 – Services for health care in the state

Number of Health Centers (Source-Department of Health (April 7<sup>th</sup> 2015))

Sr.No	District	Primary Health Center	Sub-center	Sub-district hospital	Rural Hospital	District Hospital	Medical colleges
1	Mumbai*						4
2	Thane	32	187	2	6	1	1
3	Palghar	46	305	3	9	0	
4	Raigad	52	288	5	8	1	
5	Dhule	41	232	2	6	0	1
6	Nandurbar	58	290	2	12	1	
7	Jalgaon	77	442	3	18	1	
8	Nashik	103	577	4	23	1	
9	Ahamednagar	96	555	2	23	1	
10	Pune	96	539	4	20	1	1
11	Solapur	77	431	3	13	0	1
12	Satara	71	400	2	15	1	
13	Kolhapur	73	413	4	16	0	1
14	Sangli	59	320	2	13	0	1
15	Ratnagiri	67	378	3	8	1	
16	Sindhudurga	38	248	3	7	1	
17	Aurangabad	50	279	3	10	0	1
18	Jalna	40	213	1	8	1	
19	Parbhani	31	214	2	6	1	
20	Hingoli	24	132	1	3	1	1
21	Latur	46	252	2	10	0	
22	Osmanabad	42	206	3	6	1	1
23	Beed	50	280	3	10	1	1
24	Nanded	65	377	4	12	0	1
25	Akola	30	178	1	5	0	
26	Washim	25	153	0	7	1	
27	Amaravati	56	333	4	9	1	
28	Yavatmal	63	435	3	14	0	1
29	Buldhana	52	280	2	12	1	
30	Nagpur	49	316	2	9	0	2
31	Wardha	27	181	2	6	1	
32	Bhandara	33	193	2	7	1	
33	Gondiya	39	238	1	10	1	
34	Chandrapur	58	339	3	10	1	
35	Gadchiroli	45	376	3	9	1	
	<b>Total</b>	<b>1811</b>	<b>10580</b>	<b>86</b>	<b>360</b>	<b>23</b>	<b>18</b>

\* Health services in greater Mumbai are provided through 16 Peripheral Hospitals, 5 Specialized Hospitals ( ENT, Eye, TB, Leprosy and Kasturba Hospital for Infectious Diseases), 28 Maternity Homes, 161 Dispensaries, 183 Health Posts, 23 Post Partum Centres, S.T.D. clinic, Drug-De-Addiction Centre etc. (Source - [http://portal.mcgm.gov.in/irj/go/km/docs/documents/MCGM%20Department%20List/Public%20Health%20Department/RTI%20Manuals/PubHealthDept\\_RTI\\_E02.pdf](http://portal.mcgm.gov.in/irj/go/km/docs/documents/MCGM%20Department%20List/Public%20Health%20Department/RTI%20Manuals/PubHealthDept_RTI_E02.pdf))

### Appendix 3 – Services for education in the state

Number of Primary schools (Source-Department of Primary Education, 2015)

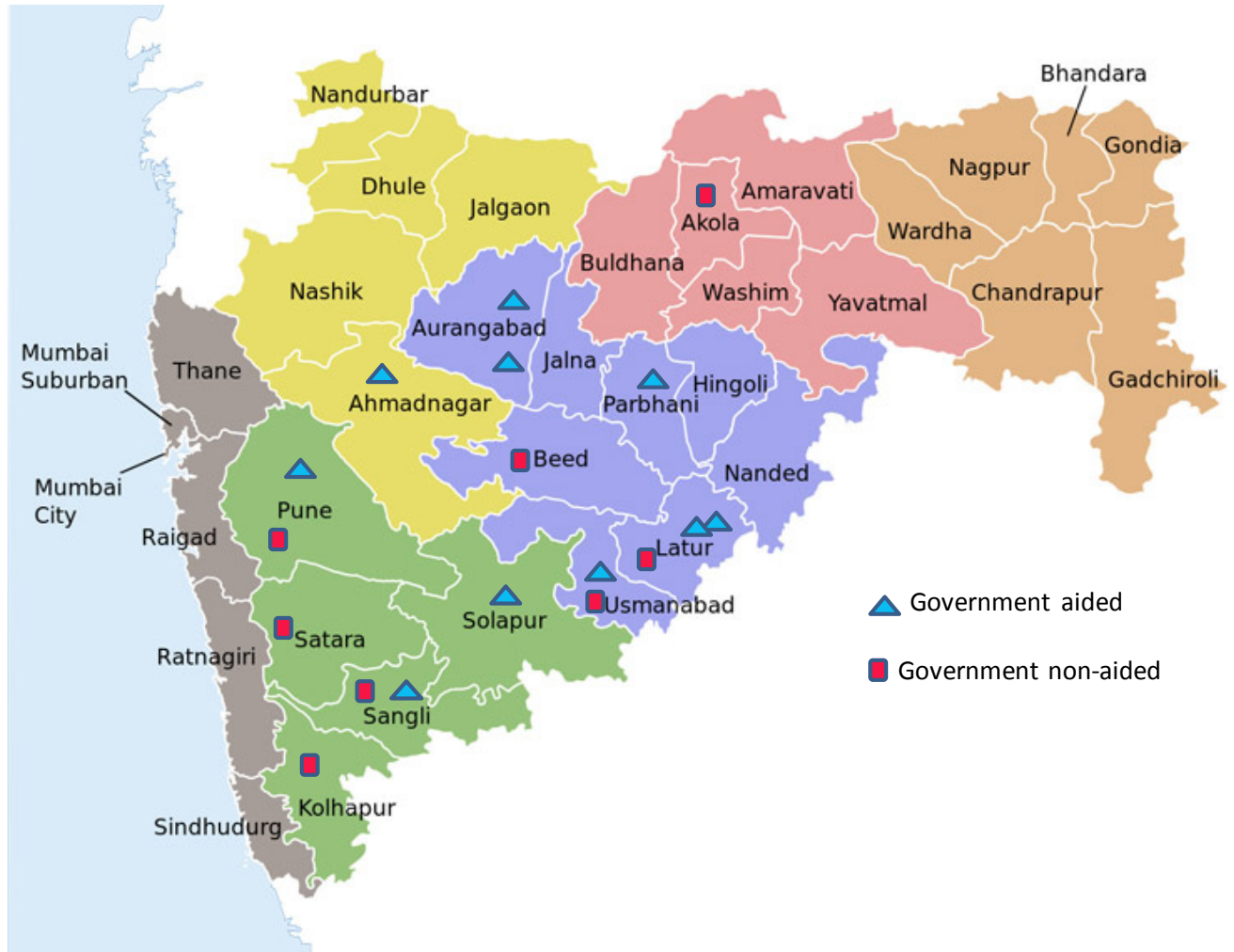
Sr. No	District	Government schools	Private aided schools
1	Thane	3673	1464
2	Raigad	2931	339
3	Ratnagiri	2777	343
4	Sindhudurga	1471	215
5	Nashik	3680	1710
6	Dhule	1160	479
7	Nandurbar	1412	241
8	Jalgaon	1928	783
9	Ahamednagar	3722	869
10	Pune	4307	1176
11	Solapur	3026	1048
12	Satara	2786	651
13	Kolhapur	2161	872
14	Sangli	1800	690
15	Aurangabad	2255	631
16	Jalna	1589	286
17	Parbhani	1175	311
18	Hingoli	884	159
19	Latur	1323	808
20	Osmanabad	1143	374
21	Beed	2432	637
22	Nanded	2253	725
23	Akola	1439	640
24	Washim	841	256
25	Amaravati	1764	617
26	Yavatmal	2245	523
27	Buldhana	1643	307
28	Nagpur	1849	985
29	Wardha	994	265
30	Bhandara	833	305
31	Gondiya	0	1108
32	Chandrapur	1681	354
33	Gadchiroli	1581	178
34	Mumbai	1251	1109
	<b>Total</b>	<b>66009</b>	<b>21458</b>

**Number of Secondary schools** (Source-Department of Secondary Education, UDISE-2014-15)

Sr. No.	Name of District	Total Schools	Government	Private Aided	Un-Aided
1	Ahmadnagar	999	27	744	218
2	Akola	447	21	317	105
3	Amravati	680	65	502	109
4	Aurangabad	802	75	428	289
5	Bhandara	304	42	214	45
6	Bid	645	72	434	137
7	Buldana	504	53	336	113
8	Chandrapur	501	45	325	126
9	Dhule	466	21	391	51
10	Gadchiroli	328	57	196	75
11	Gondiya	320	41	217	59
12	Hingoli	198	34	104	57
13	Jalgaon	782	35	617	126
14	Jalna	370	41	192	133
15	Kolhapur	909	10	715	171
16	Latur	657	54	497	89
17	Mumbai (Suburban)	145	142	3	0
18	Mumbai II	1465	15	801	625
19	Nagpur	992	67	628	293
20	Nanded	654	96	445	110
21	Nandurbar	391	65	219	99
22	Nashik	1073	87	706	275
23	Osmanabad	432	58	304	70
24	Palghar	509	65	177	254
25	Parbhani	425	53	217	146
26	Pune	1554	81	867	578
27	Raigarh	576	21	306	234
28	Ratnagiri	411	5	327	70
29	Sangli	641	3	497	132
30	Satara	715	7	547	154
31	Sindhudurg	229	1	194	28
32	Solapur	937	16	703	216
33	Thane	1259	66	461	718
34	Wardha	286	16	219	50
35	Washim	294	15	220	59
36	Yavatmal	636	75	433	126
	<b>Total</b>	<b>22536</b>	<b>1647</b>	<b>14503</b>	<b>6140</b>

## Appendix 4 – Children’s homes in the state

Distribution of children’s homes for CABA (Source-Department of Women and Child Welfare (February 2015))



## Number of Children's homes

Sr.No	District	Total government children homes for all	Children's homes for CABA (Aided)	Children's homes for CABA (Non-Aided)	Total Children's homes for CABA (Aided+non-aided)
1	Thane	5	0	0	0
2	Raigad	0	0	0	0
3	Ratnagiri	0	0	0	0
4	Sindhudurga	1	0	0	0
5	Nashik	1	0	0	0
6	Dhule	0	0	0	0
7	Nandurbar	0	0	0	0
8	Jalgaon	1	0	0	0
9	Ahamednagar	1	1	0	1
10	Pune	4	1	1	2
11	Solapur	2	1	0	1
12	Satara	0	0	1	1
13	Kolhapur	1	0	1	1
14	Sangli	1	1	1	2
15	Aurangabad	2	2	0	2
16	Jalna	2	0	0	0
17	Parbhani	1	1	0	1
18	Hingoli	0	0	0	0
19	Latur	2	2	1	3
20	Osmanabad	0	1	1	2
21	Beed	1	0	1	1
22	Nanded	0	0	0	0
23	Akola	1	0	1	1
24	Washim	0	0	0	0
25	Amaravati	4	0	0	0
26	Yavatmal	1	0	0	0
27	Buldhana	2	0	0	0
28	Nagpur	4	0	0	0
29	Wardha	2	0	0	0
30	Bhandara	0	0	0	0
31	Gondiya	0	0	0	0
32	Chandrapur	2	0	0	0
33	Gadchiroli	1	0	0	0
34	Mumbai	1	0	0	0
35	Palghar	0	0	0	0
	<b>Total</b>	<b>43</b>	<b>10</b>	<b>8</b>	<b>18</b>



## **Appendix 5 – List of organizations that participated in the assessment**

1. Amchich Amche, Sangli
2. Community Aid Sponsorship Programme (CASP), Pune
3. Committed Communities Development Trust (CCDT), Mumbai
4. Deep Griha Society, Pune
5. Humsaya Welfare Trust, Mumbai
6. Kranti Mahila Sangh, Solapur
7. Niramaya Arogya Dham, Solapur
8. NMP+ (Network of Maharashtra By People Living With HIV/AIDS), Mumbai and Pune
9. NPM+ (Network By People Living with HIV In Mumbai), Mumbai
10. NPP+ (Network of Pune By People Living With HIV/AIDS), Pune
11. NSOP (Network of Solapur By People Living With HIV/AIDS), Solapur
12. Param Prasad Charitable Trust, Solapur
13. Dr. Paramshetty, Sangli
14. Prayas, Pune
15. Sahara Aalhad, Pune
16. Sangram, Sangli
17. Sarva Seva Sangh, Pune





